

**The Emotional and Social lives of Parents with a Learning Disability and the Impact of a Positive Parenting Programme on Psychological Well-Being – A Pilot Study.**

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Clinical Psychology**

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## **DECLARATION**

"I certify that this thesis is a true and accurate account of the work carried out. It has been composed by myself and the work herein is my own. It has not been submitted for any other degree or professional qualification".

Signed.....

**Julie Cottrell**

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## **ABSTRACT**

Recent government documents have highlighted the need to improve services for parents with a learning disability. Despite these parents being identified as one of the most vulnerable groups for mental-health difficulties, mental health and other important areas of parenting (e.g. social support) have been neglected with these parents. Likewise, services running parenting programmes have failed to identify parents with learning disabilities and therefore adapt parenting groups or assessments to suit this population. The aim of this study was therefore to investigate the levels of parental stress, anxiety and depression, child behaviour problems, social support and parenting difficulties in parents with learning disabilities (PART A) and to set-up and evaluate the effect of an adapted piloted positive parenting programme (Triple P) on these variables (PART B). Parent satisfaction with the groups was also investigated. With the exception of the parenting skills assessment, results were compared with a control group of parents without a learning disability. Both groups were found to be experiencing significant levels of parental stress, anxiety/depression and child behaviour problems and no differences were found between the groups. The parents with a learning disability were found to have a lower number of social supports but rated these supports as more helpful than the control group. Intervention resulted in a significant decrease in parental stress for the parents with a learning disability only and neither group had decreased anxiety/depression or child behaviour scores. Intervention did however lead to an increase in social support and appropriate parenting strategies for the parents with a learning disability. Both groups rated the Triple P programme highly in terms of consumer satisfaction. The clinical implications of the levels of anxiety and depression of the parents with a learning disability are discussed, including the need for specialist provision for this population and co-ordination between child and learning disability specialities in Tayside. Areas for further research are also noted.



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## **CHAPTER ONE**

### **INTRODUCTION**

## 1.1. GENERAL INTRODUCTION

Until recently there has been a limited amount of research with regard to parents with a learning disability. Booth & Booth (1993a) note that what research exists is largely American, throwing little light on the adequacy of support services in the UK. British literature also shows a bias in the welfare of children of parents with a learning disability, rather than in the needs of the parents. Government reports recently highlighted the neglect in services for these parents. The Department of Health (DOH, 2000) report, *'A Jigsaw of Services-Inspection of Services to Support Disabled Adults in their Parenting Role'* reported on the piecemeal and scanty nature of services available for people with learning, physical and sensory impairments. The lack of co-ordination between services for children and parents was also highlighted. Family needs (e.g. services, care plans) were being met in only 30% of cases across each of the eight councils investigated and disabled parents felt family support was only 'a pipe dream for them' (p.1). The Government white paper, *Valuing People, a New Strategy for Learning Disability for the 21<sup>st</sup> Century* (2001) highlighted people with a learning disability have a right to marry and have a family. It recognised the need to improve parenting initiatives and support for these parents.

Consistent with these government initiatives, this pilot study aims to identify parents with a learning disability in Tayside region who are having difficulties managing their children, assess coping and level of social support and offer a new service i.e. a positive parenting programme, the first of its kind for parents with a learning disability in Tayside. The introduction to this study opens with a review of historical attitudes towards parenting and learning disability (section 1.2.) and demonstrates how it remains an issue of extreme controversy (Tymchuk, 1990b).

The predictors of successful and unsuccessful parenting by parents with a learning disability are reviewed in section 1.3 which concludes with a discussion of the small amount of available research on social support of parents with a learning disability. Section 1.4 highlights the paucity of research on the emotional lives of parents with a learning disability, while the longstanding assumption that people with a learning disability are unable to adequately care for a child is addressed in section 1.5. Section 1.6. provides a background to general parenting programmes, including the Positive Parenting Programme (Triple P). Parent training for parents with a learning disability and the controversial question of whether parents with a learning disability can be trained to be adequate parents is addressed in section 1.7. The aims and hypotheses of the current study are then outlined in section 1.8.

## **1.2. PARENTING AND PEOPLE WITH A LEARNING DISABILITY**

McCarthy (1999) suggests that in order to understand current attitudes towards the sexuality of people with a learning disability, it is necessary to understand how it was viewed historically. This section therefore briefly outlines the history of sexuality and learning disability, including the prevalence of parents with a learning disability and beliefs surrounding this population.

### **1.2.1. Definition of a learning disability**

The British Psychological Society (BPS, 1991) specify that all of three criteria must be met for a diagnosis of learning disability: (1) significant impairment of intellectual functioning as measured on an individually administered intellectual assessment i.e. an IQ of less than 70 (2) significant impairment in adaptive/social functioning (e.g. communication, home-living) and (3) the intellectual and social impairments have been acquired before 18 years of age.

### **1.2.2. Historical attitudes towards sexuality and learning disability**

Parenting has been viewed as undesirable for people with a learning disability for a number of years (Pixa-Kettner, 1996). At the turn of the 20<sup>th</sup> Century the eugenics movement resulted in preferential admission of 'feeble-minded' women of childbearing age to segregated institutions (Craft, 1993). It was believed that sexual relationships would lead to the transmission of 'mental unfitness' to any potential children. To prevent this, females were not released until menstruation ceased (Bass, 1965) and in 1950 compulsory sterilisation laws were introduced. Until recently, sterilisations were carried out on a large scale in the USA as a prerequisite for discharge back into the community (Craft, 1993). While the Mental Deficiency Act made marriage illegal in 1913 for 'morally defective' people, some countries still have laws prohibiting marriage by people with a learning disability.

People with a learning disability were also stereotyped as either perpetual children who were thought not to be sexual beings, or in contrast, as potentially dangerous and unable to control their sexual urges (Cambridge, 1996). These two belief systems, although contradictory, (Craft, 1987), had a powerful influence over services for people with a learning disability and McCarthy (1999) believes these views can still be observed today (McCarthy, 1999).

### **1.2.3. Normalisation?**

In the past two decades the concept of normalisation has been applied to people with a learning disability, the principle being to promote an existence as close to normal living conditions as possible (Bank-Mikkelsen, 1980). While advances have been made towards an ordinary life in the community in terms of housing, employment and

education (Ward, 1993) for people with a learning disability, Feldman (1986) notes that the normalisation principle has not extended to marriage and child rearing to the same extent. Segregation is, however, no longer seen as an acceptable method of pregnancy prevention and courts are banning involuntary sterilisation (Hayman, 1990, Vogel, 1987). Denial of parenthood on the basis of disability alone is now viewed as an unacceptable infringement of the right to reproduce (Llewellyn, 1990). A number of recent publications have also highlighted the sexual rights of people with a learning disability (e.g. Cambridge, 1996, Craft, 1993, McCarthy, 1999). Despite this, negative attitudes persist with regard to sexuality and learning disability (Johnson & Davies, 1989) and a recent review article (Aunos & Feldman, 2002) concluded health professionals continue to support sterilisation as a form of contraception for this population.

The assumption that parents with a learning disability cannot provide adequate care for a child has, therefore, been slow to change and an intellectually disabled person may still encounter ambivalent attitudes from family, friends and professionals (Llewellyn, 1990). For people with a learning disability, the ability to parent is questioned at the outset (Gath, 1993) and they tend to be prejudged before any fault is established (Tymchuk, 1990a). The words of Whitman & Accardo (1990) only a decade ago may, therefore, still reflect the attitude of many people today: 'parenting failure of significantly retarded adults...would seem to be not whether, but when...' (p. 70). Tymchuk (1990b) argues that much of what we believe today about parenting and learning disability was derived from a particularly restrictive period of time where bias was rife and suggests it is now time to discard or re-examine these earlier descriptions.

#### **1.2.4. Prevalence of parenting in learning disability**

There have been no national surveys conducted in the UK that have attempted to identify the prevalence of parents with a learning disability (DOH, 2000). The limited surveys that have been attempted have been being dogged by methodological problems (Pixa-Ketner, 1996) including different IQ cut-offs, inclusion of both physical and learning disability and differences between countries in terminology of the terms learning disability and learning difficulties.

Whilst the exact number of disabled parents in the UK is, therefore, not known, the Department of Health (2000) have estimated that there may be around 1.2 to 4 million parents with learning, physical and/or sensory impairments. What is certain is that as a result of decreased segregation, withdrawal of involuntary sterilisation and wider opportunities for independent/community living, the numbers of parents with a learning disability are steadily increasing and will probably continue to do so (Attard, 1986, O'Brien & Tyne, 1981, Perrin & Nirjie, 1985).

#### **1.2.5. Beliefs surrounding parenting and learning disability**

Concerns by both the public and professionals about parenting by people with a learning disability have centred around four main beliefs that: (1) they produce more children than the norm; (2) their children will be born with a learning disability; (3) their children will be poorly cared for and (4) they cannot be trained to be adequate parents.

In relation to the first belief, studies have indicated that parents with a learning disability have in fact the same number or fewer children than the norm (Andron &

Tymchuk, 1987) In early studies Ainsworth, Wagner & Strauss (1945) and Charles (1957) reported that parents with a learning disability averaged 2.3 children per mother, which was slightly less than the national average at the time. This data has been substantiated by others (e.g. Craft & Craft, 1979, Mattinson, 1971, Peck & Stephens, 1965). It has been reported that people with a learning disability prefer to have a small number of children due to the costs and effort in raising them (David, Smith & Friedman, 1976).

The second belief, that children born and raised by parents with a learning disability will be at significant risk for cognitive delay (Martin, Ramey & Ramey, 1990), has been supported by empirical research, particularly when parents have an inheritable form of learning disability (Laxover, Gilderdale & Ridler, 1973). Studies (Akesson, 1961, Reed & Anderson, 1973, Scally, 1973) have generally found that the majority of these children are of higher intelligence than their parents. However, it is noted (Priest, Thuline, La Veck & Jarvis, 1965, Reed & Reed, 1965, Shaw & Wright, 1960,) that 40% of these children will have an IQ within the learning disability range.

Gillberg & Geijer-Karlsson (1983) note that it is unclear if these findings are due to being raised by a parent with a learning disability per se or the effects of being raised in an impoverished environment. Brandon (1960) found slight differences in the IQ of offspring of institutionalised women depending on where their children were raised. Orphanage upbringing resulted in lower IQ than foster care or institutional upbringing. Keltner, Wise & Taylor (1999) controlled for any confounding effects of poverty and found that developmental delay was identified by the age of 2 years in 42% of children with mothers with a learning disability and 12% of children with

mothers without a learning disability. This suggests that being raised by a mother with a learning disability can have detrimental effects on child development that cannot be attributed to poverty alone. Feldman & Walton-Allen (1997) also matched groups on socio-economic status and concluded that the home environment, cognitive and behavioural functioning of the offspring of parents with a learning disability were lower despite similar poverty levels.

The third and fourth set of beliefs surrounding adequacy of parenting by persons with a learning disability merits its own section and has been reviewed in section 1.5.

#### **1.2.6. Summary**

Research suggests that negative attitudes towards parenting by people with a learning disability continue to persist. While there is a *higher* incidence of learning disability amongst children of parents with a learning disability, the assumption that all children of parents with a learning disability will have learning disability is false (Sheerin, 1998), as is the belief they produce more children than the norm. Despite the introduction of the principles of normalisation, recent research (e.g. Aunos & Feldman, 2002) suggests the topic of disability and parenthood continues to sit uncomfortably with professionals and societies.

### **1.3. WHAT PREDICTS SUCCESSFUL PARENTING BY PARENTS WITH A LEARNING DISABILITY?**

The next section explores the limited amount of research that has been conducted on the parameters of successful and unsuccessful parenting by persons with a learning disability. Social support as a predictor of parenting is also reviewed. First, the



predictors of child maltreatment in the general parenting population are briefly reviewed and reference to the general parenting population is also made throughout this section.

### **1.3.1. Determinants of parenting in the general population**

In terms of risk factors for child maltreatment, there is strong empirical support in the general parenting population for (a) negative maternal attitude towards the pregnancy (Altemeier, O'Conner, Vietze, Sandler & Sherrod, 1982); (b) high levels of perceived social stress, such as poor health, inadequate finances and unhappy life events (Altemeier et al., 1982, Friedrich & Wheeler, 1982); and (c) low socio-economic status. Other risk factors include parent's criminal record, loss of previous child, low intelligence, history of child maltreatment, negative maternal traits, absence of social support, social isolation and parental substance abuse (Epps & Jackson, 2000). The following risk factors discussed in this chapter are therefore not necessarily unique to parents with a learning disability (Craft, 1993). Many of the risk factors of the general parenting population have, however, not yet been researched with parents with a learning disability (e.g. parental substance abuse) and therefore the following factors have been selected based on available research literature.

### **1.3.2. Intelligence**

Research has indicated (e.g. Tymchuk & Andron, 1990) that IQ is not a good predictor of parenting success or responsiveness to parent training intervention until it falls below 60. Tymchuk & Andron (1994) suggest that parents with adequate reading recognition and comprehension may do better by being able to make use of information sources such as parenting manuals and instructions on high-risk

household products. Borgman (1969) suggested that above an IQ of 60, other factors play a greater role in predicting parental adequacy. These factors are discussed next.

### **1.3.3. Socio-Economic Status**

Parenting occurs in a socio-economic context and poverty has been found to correlate with a whole number of factors ranging from poor housing to family stress. These are likely to affect *any* child's physical, intellectual, social and emotional development (Pringle, 1975). Despite the finding that over half of mothers with a learning disability come from deprived backgrounds (Edgerton, 1967, Edgerton & Berovici, 1976, Gillberg & Geijer-Karlsson, 1983, Mattinson, 1971), the effect of socio-economic factors on parenting has been largely ignored with this population. Some early studies (Mattinson, 1971, Mickelson, 1947, Mitchell, 1947) did highlight that the parents providing unsatisfactory care were receiving financial assistance. The few studies that have controlled for poverty (see section 1.2.5), indicate that parenting difficulties are still greater for women with a learning disability and suggest other variables may also play a role, as discussed next.

### **1.3.4. Childhood experiences and upbringing**

The childhood experiences of parents with a learning disability have received little attention (Llewellyn, 1990). Gath (1988) notes that institutionalised parents would have had no experience of family life at all and those admitted in later childhood had often experienced very poor upbringing and bad relationships. Dowdney, Skuse, Rutter, Quinton & Mrazek (1985) comment that such poor experiences would not prepare even those without learning disability to be adequate parents. Women raised in institutions were offered no parental training and Gillberg & Geiger-Karlsson

(1983) note that it is, therefore, to be expected that these women would do poorly in raising children. Tymchuk & Andron (1990) found that mothers with parental role-models that provided some nurturing were clearly more nurturing of their own children than those with histories of abuse. People with a learning disability are particularly vulnerable to being abused both as children and adults (Brown, Stein & Turk, 1995, Turk & Brown, 1994), a factor also associated with inadequate parenting (Rutter, 1989).

### **1.3.5. Characteristics of the child**

Child characteristics such as age, sex, ordinal position and temperament have been found to influence the quality of parenting in the general population (Belsky & Vondra, 1989, Dowdney, 1988, Maccoby & Martin, 1983). Brown & Harris (1978) found high parental stress was associated with having three or more young children. Such variables have largely been ignored in the literature on parents with a learning disability (Dowdney & Skuse 1993).

One study by Gath (1995), suggested that the number, ages and spacing of children plays a major role in determining whether a parent with a learning disability will be able to cope. Gath (1995) notes that in many cases parenting was adequate with one child, just about good enough with two but completely unsatisfactory with a third or as the children grow older. It has been reported that parents with a learning disability find the demands of middle childhood and adolescence particularly difficult to cope with (Whitman & Accardo 1990) as they may no longer be more cognitively able than the child and responsibilities outgrow the capacity to manage. Borgman (1969) did, however, report on a small number of mothers facing neglect proceedings where no

relationship was found between number of children and inadequate childcare. Having a child with a developmental or medical problem may also cause difficulties, which taxes even the most capable of parents (Tymchuk & Andron, 1994).

#### **1.3.6. Co-morbidity and characteristics of the spouse**

The outlook for the children is poorer when both parents have a learning disability or either have a concomitant medical (e.g. visual impairment), emotional or physical disability (e.g. cerebral palsy, epilepsy) which they must cope with while still providing care (Lynch & Bakley, 1989, Tymchuk & Andron, 1988, 1990).

Gath (1993) highlights the cycle of deprivation affecting institutionalised woman. While the negative effects of poor childhood experiences can be buffered by later factors, particularly a stable spouse and good living conditions (Quinton, Rutter & Liddle, 1984), these powerful protective factors are not commonly encountered during the lives of women with a learning disability. Marital discord has also been associated with increased risk of stress and parenting problems in the general population (Emery & Turner, 1993).

#### **1.3.7. Social support**

##### **1.3.7. (a) Lack of research on parents with a learning disability**

It is well known that perceived social support is one of the most consistent and strongest predictors of personal adjustment (Sarason, Sarason & Pierce, 1994). Andresen & Telleen (1992) conducted a review of 66 studies of social support and parenting in the general population. Significant relationships were found between emotional/material support and parenting behaviours. None of these studies included

mothers with a learning disability. Newton, Horner, Ard, LeBaron & Sappington (1994) have criticised the lack of attention to the investigation of social relationships and support for people with a learning disability in general, despite the almost universal finding that parents with a learning disability are among the most socially isolated and financially disadvantaged in society (Andron & Tymchuk, 1987, Australian Bureau of Statistics, 1994, Booth & Booth, 1995, Rosenberg & Mctate, 1982). Booth & Booth (1995) suggest that parenthood exacerbates the social isolation typical of people with a learning disability. This social isolation has been attributed to poverty, the demands of childcare, social skills deficits which may inhibit acceptance by others, the parent's sense of being different and problems which are thought to overburden the informal support available (Andron & Tymchuk, 1987, Booth & Booth, 1995, Llewellyn, 1995).

Single parenthood is also a well-known risk factor in the general population for parenting difficulties (Cox, Puckering, Pound et al., 1987, McNamee, Lipman, Friedrich et al., 1996, Munroe, Boyle & Offord, 1988,) yet despite the finding that mothers with a learning disability are less likely to be married, (Budd & Greenspan, 1986, Zetlin, Weisner & Gallimore, 1985) this area has also been neglected with this population. Llewellyn, McConnell, Cant & Westbrook (1999) note that where studies on social support and parents with a learning disability exist they have tended to focus on the support providers' viewpoint.

### **1.3.7.(b) Social support as a predictor of neglect by parents with a learning disability**

Tymchuk & Andron (1990) are among the few investigators to have addressed the issue of social support and parents with a learning disability. They found that the best predictor of neglect in this group was the absence of suitable societal (e.g. parenting classes) or familial supports which can help prevent neglectful conditions (Tymchuk & Andron, 1990, Zetlin, 1986, Zetlin, Weisner & Gallimore, 1985). Mothers living with a relative and those willing to participate in training programs were less likely to have their children removed (Tymchuk & Andron, 1990, Whitman, Graves & Accardo, 1989).

### **1.3.7. (c) Whom do parents with a learning disability turn to for support?**

Llewellyn et al. (1999) studied the structural and functional characteristics of support network of 25 mothers with a learning disability. They found that whether mothers were relying on formal or informal support depended on their living arrangements. Mothers living with their parents had less contact with professional agencies. Mothers living alone were found to be very lonely, relied on service-centred networks and had little opportunity to meet other parents. Llewellyn et al. (1999) found that the support networks of mothers living with a partner were the most heterogeneous in that they accessed both formal and informal support.

Mothers with a learning disability often find it difficult to identify friends and neighbours whom they can turn to for support (Llewellyn et al., 1999). An unusually high proportion have no contact with their immediate family and receive very little, if any, support from extended family, neighbours or other community members (Andron

& Tymchuk, 1987, Llewellyn, 1995, Rosenberg & McTate, 1982, Whitman & Accardo, 1990). Whitman, Graves & Accardo (1990) found that whilst 66% of learning disabled parents perceived learning, behavioural and medical problems in their children, fewer than 15% were able to locate appropriate support.

#### **1.3.7. (d) Do parents with a learning disability find their supports helpful?**

Zetlin et al. (1985) attributed the success of parents with a learning disability to the positive support from their own parents, however, this is not always the case. Tucker & Johnson (1989) studied 12 parents with a learning disability and found that social support could either be competence promoting (offered support and instilled a belief in the parents' own capabilities) or competence inhibiting (belittled the parents' efforts and intervened for the child's sake only). Llewellyn et al. (1999) found that living with a parent often led to disempowerment of the women, particularly in the area of parenting competence. On average, parents with a learning disability can list about six social supports, comprising both family and professionals (Llewellyn et al., 1999, Stenfert-Kroese, Hussein, Clifford & Ahmed, 2002). Stenfert-Kroese et al. (2002) found that only half of these were perceived as helpful.

#### **1.3.7. (e) Providing optimal support for parents with a learning disability**

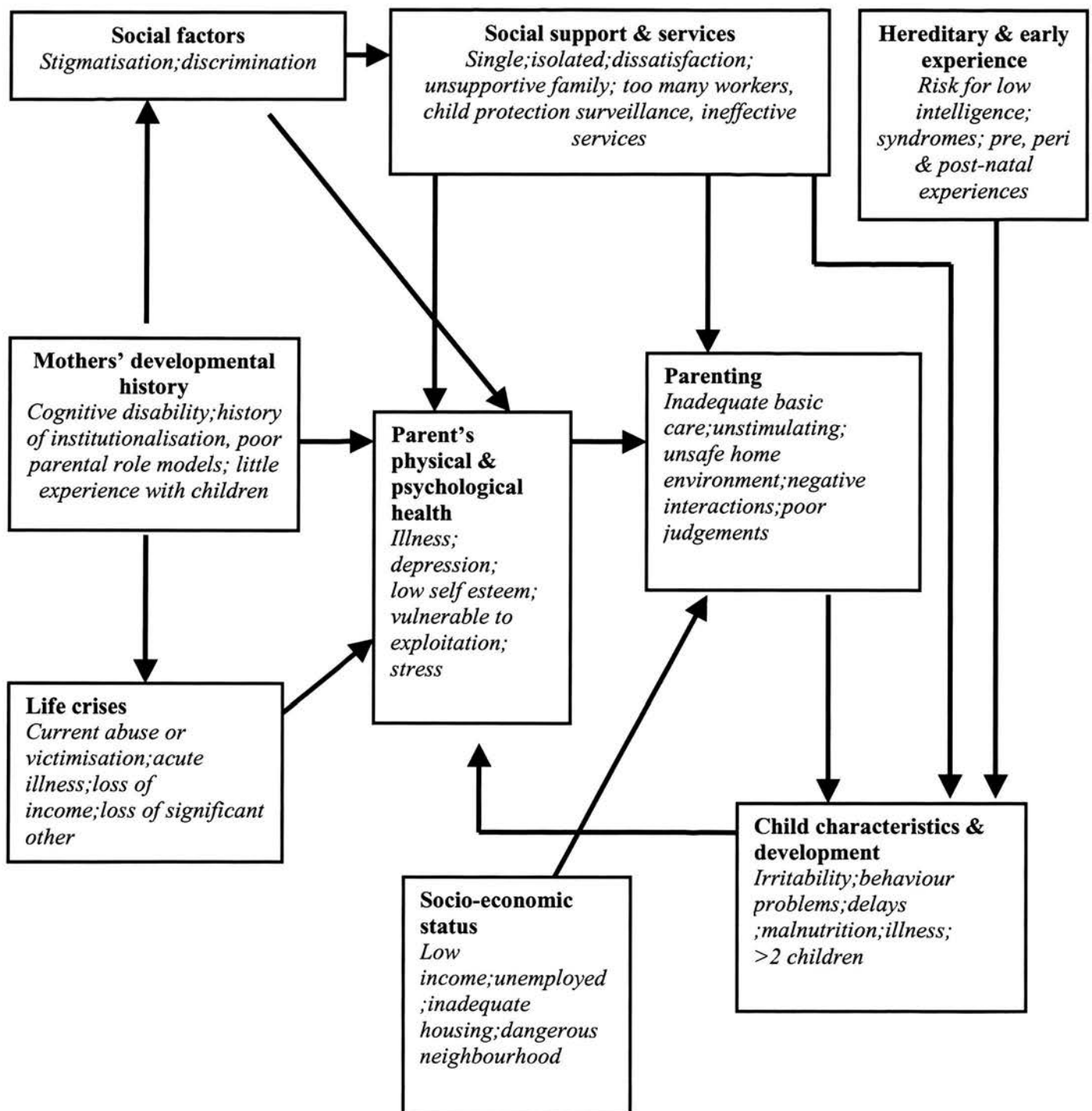
Tymchuk & Andron (1990) state that a major predictor of neglect is a longstanding discrepancy between the mother's own resources (e.g. knowledge, skills and experience) and the needs of her child, family and of herself. A lack of support from an adult without a learning disability has been cited as one of the main predictors of child removal (Seagull & Scheurer, 1986). Supports, which are matched closely to the needs of the mother's learning style and learning capacity, have been found to be

particularly helpful (Tymchuk, 1990a). Tymchuk (1990a) and other researchers suggest critical characteristics of support include availability (transportation provided), comprehensiveness (covers all needs including medical, educational and financial), frequency and duration (provided often and long enough), place (provided in the home environment for maximum generalisation) and being provided with staff who are trained specifically to work with parents with a learning disability (Budd & Greenspan, 1985, Espe-Sherwindt & Kerlin, 1990, Lynch & Bakley, 1989, Tymchuk & Andron, 1990).

#### **1.3.8. Summary**

Provided it is above 60, IQ alone is not a risk factor or predictor of parenting success or purposeful child abuse (Tymchuk, 1990a). Many of the problems experienced by parents with a learning disability can be attributed to poverty, poor childhood experiences and lack of support rather than parental intelligence per se (Quinton & Rutter, 1984) Most of these factors are associated with difficulties in parenting by most people in society (Tymchuk & Andron, 1994). The best predictor of inadequate parenting in both the learning and non learning disabled population appears to be the absence of suitable social or familial supports (Tymchuk, 1990a). Feldman (2002) has developed an interactional model of parenting applicable to parents with a learning disability which summaries the factors discussed in this section and has been illustrated in Figure 1.





**Figure 1:** An interactional model of parenting applicable to parents with a learning disability. Items in italics are possible impediments to effective parenting and optimal child outcomes.

## **1.4. MENTAL HEALTH AND PARENTING**

This section explores the role of mental health, a key factor affecting quality of parenting and a child's developmental outcome (Beeber & Miles, 2003). Despite mental health being recognised as one of the most debilitating influences on parenting, in the main, research has tended to be conducted on parents without a learning disability. The general research findings are reviewed here and gaps in the literature with regards to parents with a learning disability are highlighted.

### **1.4.1. The vicious cycle of mental health and parenting**

McLean (1976) proposed that depression or anxiety predisposes parents to cope less effectively with parenting. Parental mental health problems can create a vicious cycle of stressful child-parent interactions where the affective behaviour of parents can in turn lead to children having difficulty regulating their own behaviour. In addition, a parent with a mental health problem is likely to have marital problems and a lower tolerance threshold for children's behaviour (Creasey & Jarvis, 1994, Murray, 1997).

McLean (1976) proposed the cycle continues as the level of children's negative behaviour, especially anxiety, aggressiveness and hyperactivity, significantly affects parental stress levels (Gelfand, Teti & Fox, 1992) and confidence in their parental roles (Kyrios & Prior, 1990).

### **1.4.2. Parental mental health and child psychopathology**

Problems in childhood including attention deficit hyperactive disorder (Lin & Chung, 2002), depression, substance use and poor school performance (Leinonen, Solantaus & Punamaki, 2003) have been found to be strongly associated with maternal

depression and other mental health related conditions (Bee et al., 1986, Brody & Forehand, 1986). Indeed, children of depressed parents are not only at increased risk for clinical depression (Dowdney & Coyne, 1990) but a full range of problems of adjustment including internalising and externalising problems and poorer physical health than children of control parents (Beardslee, Schultz & Selman, 1987, Dowdney & Coyne, 1990, Weissman, Wickramaratne, Warner et al., 1987). There is, however, a dearth of such research relating to parents with a learning disability. One study (McGaw & Sturmey, 1993) noted that while children of mothers with a learning disability are susceptible to delays in speech and language (Ramey & Campbell, 1984, Feldman, Case, Towns & Betel, 1985) it is particularly likely to occur in those families where the children are living in isolated surroundings and the mother is depressed.

#### **1.4.3. Depression and parents with a learning disability**

Despite the wealth of information on the incidence and effect of depression on parenting in the general population (Dowdney & Coyne, 1990, Ge, Conger, Lorenz & Simons, 1994, Kaslow, Graydeering & Racusin, 1994, McLoyd, Jayaratne, Ceballo & Borquez 1994, Whitbeck, Simons, Conger, Lorenz, Huck & Elder, 1991) the incidence of depression and effect on parenting in parents with a learning disability has been grossly neglected. While *people* with a learning disability in general have been found to exhibit depression symptoms more often and to a greater degree than people without an intellectual disability (Reiss, Levitan & McNally, 1982) only one study appears to exist examining depression in *parents* with a learning disability. Tymchuk (1994) found that 39% of a group of mothers with a learning disability scored above 17 on the Beck Depression Inventory, compared with only 13% of the

mothers with a learning disability. More of the women with a learning disability described themselves as failures, being discouraged about the future and self-critical. A significant relationship was found between high scores on the BDI and reported history of abuse or neglect in childhood. The mothers employed in this study were however involved in a community and University hospital-based support programme. Due to the support these parents were receiving they may therefore be an unrepresentative sample of parents with learning disabilities and an underestimation of depression in this population. Tymchuk & Andron (1994) note that characteristics of mothers with a learning disability who do well include no concomitant emotional disturbance and low-stress.

#### **1.4.4. Stress and parenting**

Stress is experienced when the subjective demands of a situation outweigh the individual's ability to cope (Straus & Kantor, 1987). Parenting has been identified as a potential source of stress and role adaptation (Pearlin & Turner, 1987). How much stress a parent will experience is mediated by characteristics of the parent, child and environment (Belsky, 1984, Dohrenwend & Dohrenwend, 1969).

Maternal stress may disrupt optimal parenting practices (Patterson, DeBaryshe & Ramsey, 1989) and is associated with lack of warmth and responsiveness (Belsky, 1984), negative parent-child interactions (Webster-Stratton, 1988), child maltreatment (Rodgers, 1993), increased risk of child developmental delay (Bee et al., 1986) and behavioural problems (Patterson et al., 1989). Socially isolated mothers who report feeling stress are more negative, confrontational and unpredictable with their children (Dumas & Wahler, 1985, Panaccione & Wahler, 1986),

#### 1.4.5. Stress and parents with a learning disability

Only two studies appear to have emerged examining level of stress in parents with a learning disability (i.e. Feldman, Leger & Walton-Allen, 1997, Tymchuk, 1993) despite the fact that many may be experiencing the *multiple* disadvantages known to predispose stress in the general population such as marital discord (Brown & Harris, 1978, Garmezy & Rutter, 1983), single parenting (Weinraub & Wolfe, 1983), social isolation, (Dumas & Wahler, 1985), dissatisfaction with supports (Weinraub & Wolfe, 1983) and unemployment/unskilled jobs (Brown & Harris, 1978). Other life stresses may include a child with disabilities (Benedict, Wulff & White, 1992) and/or behavioural problems (Eyberg, Boggs & Rodriguez, 1992), inadequate housing, poor role-models, problematic personal histories and poor health (Booth & Booth, 1994).

Furthermore, parents with a learning disability may experience specific stresses such as a constant threat of child removal (Hayman, 1990), stigmatisation (Abramson, Parker & Weisberg, 1988) and a history of failure and learned helplessness (Floor & Rosen, 1975). Low maternal intelligence may be an additive factor for some of the children for whom the outcome is poor (Garmezy, 1991, Schaffer, 2000). Edmonds (2000) cautions however to be mindful that none of these factors necessarily lead to failure to parent just as the absence of such stresses does not necessarily make a good parent.

In a rare study, Feldman et al. (1997) compared the Parenting Stress Index (PSI, Abidin, 1995) scores of 82 mothers with a learning disability with published norms of this scale. The mothers with a learning disability were found to be experiencing clinically significant levels of stress, especially those with school-age children. The

authors hypothesise that as children grow older they may take advantage of their parents' disabilities. Feldman, Varghese, Ramsay & Rajska (2002) also found that those with lower levels of stress on the PSI had more positive support networks and parent-child interactions. The IQ cut-off (IQ<80) used in these studies are, however, problematic and as discussed later in reference to this methodological flaw in several other papers on 'learning disability' (section 4.4.), does not comply with the BPS (1991) and AAMR (1992) definition of learning disability (IQ<69).

When compared with a non learning disabled control group, Tymchuk (1993) found that mothers with a learning disability had higher scores on the anxiety and adjustment subscales of the Psychopathology Instrument for Learning Disabled Adults. Scores on the anxiety subscales were related to being abused or neglected as children and adjustment scores were related to reports of abusing their own children.

This gap in the literature on the mental health of parents with a learning disability reflects limited attention paid to the emotional lives of people with a learning disability (Arthur, 2003, Garber, 1991, Hollins & Evered, 1990, Jones & Bonnar, 1996, Tharinger et al., 1990, Wagner, 1991, Wenz-Gross & Siperstein, 1996).

#### **1.4.6. Summary**

While it is well documented that 'parental' mental health problems are a major risk factor for poor parenting practices, deviant child behaviour, psychopathology and later affective disorders (Abidin, 1990, Beardslee, Keller, Lavori, Staley & Sacks, 1993), only two groups of researchers (Feldman et al., 1997, Tymchuk, 1993) have given attention to the mental health of mothers with a learning disability. None of the

general 'parenting' studies have included parents with a learning disability, despite the predisposition of this multi-disadvantaged group to mental health problems. Feldman et al.'s (1997) study is the first to show parents with a learning disability do indeed endure clinically significant levels of depression and stress.

## **1.5 PARENTAL ADEQUACY BY PARENTS WITH A LEARNING DISABILITY**

The following section addresses the issue of whether parents with a learning disability provide adequate parenting and the problems in defining 'adequate care'. While it is stressed that the skills of parents with a learning disability may vary greatly from parent to parent, some general difficulties that having a learning disability may cause a parent are discussed, as are the possible consequences on the development of the child.

### **1.5.1. What is 'adequate parenting?'**

Measuring adequacy of childcare by parents with a learning disability has been problematic due to the lack of agreement over what precisely constitutes adequate or inadequate parenting (Tymchuk, Andron & Unger, 1987). The Children's Act (DOH, 1989) provides only general indicators about adequate parenting, stating parents should (a) provide love and affection (b) perform household tasks (c) attend to the child's physical needs and (d) provide cognitive stimulation. Andron & Tymchuk (1987) note the limitations of these non-specific pointers, for example what constitutes basic health care? Craft (1993) also notes that the needs of children change over time, which raises questions such as when are children old enough to attend to their own physical needs?

In terms of parenting style, there is a reasonable consensus on the specific dimensions of parenting that are most important for children's optimal development (Greene & Kilili, 1998, Harman & Brim, 1980, Pringle, 1975, Rutter, 1975). Thus parenting skills are thought to include sensitivity to children's cues and needs at different developmental stages, in knowing how to play and talk with children, the use of effective disciplinary techniques, providing safe but reasonable limits, being committed to children even through difficult times and helping them achieve their potential. Rutter (1989) defined parenting as the provision of an environment encouraging both cognitive and social development.

#### **1.5.2. Good-enough parenting**

Winnicott (1965) proposed that parents do not have to be 'perfect' but 'good enough'. Cooper (1985) notes that in times of frustration and stress it is natural for good-enough parents to experience negative as well as positive feelings towards their child. Gath (1988) states there is no evidence to support the notion that mild learning disability in itself is a bar to the standard of good enough parenting and there is indeed not one condition that automatically disqualifies anyone from parenting.

#### **1.5.3. Do parents with a learning disability provide adequate care?**

Overall, the evidence shows that while some parents with a learning disability are unable to provide adequate care for their children there are others who can (Tymchuk et al., 1987). In an early study, Mickelson (1947) studied ninety 'feeble-minded' parents and reported that 42% were providing satisfactory care, 32% questionable care and 26 % unsatisfactory care to their children. Floor, Baxter, Rosen & Zisfien (1975) found that whilst some of the childcare from previously institutionalised



parents was questionable by 'middle-class standards', other children were receiving adequate care and proper medical attention and affection from both parents.

Brandon (1957) asked professionals to rate 25 mothers with a learning disability for parental adequacy. Twenty were judged as having normal mothering ability and five rated low and judged to be in need of help. Mattinson (1971) found that in the majority of families with at least one parent with a learning disability, the health, hygiene and clothing needs of the children were rated satisfactory. Martin et al. (1990) concluded that the homes of 22 families in their group of mothers with a learning disability were inadequate, and 19 were adequate.

Other studies have had less positive findings. Peck & Stephens (1965) reported on a group of five parents with a learning disability, of which only one was managing 'reasonably well'. Scally (1973), in a large-scale survey found that 62% of children from a sample of parents with a learning disability were not being cared for adequately. This study, however, took no account of the other factors that influence adequate childcare, such as mental illness of the parent, marital harmony, number of children and economic status of the family. Several authors have reported that such families have required extensive assistance for everyday domestic and childcare needs (Green & Paul, 1974, Mitchell, 1947, Sheridan, 1956) and have raised serious implications that the family cannot manage without extensive assistance.

#### **1.5.4. Methodological flaws in studies of parental adequacy**

Llewellyn (1990) notes that many of these earlier studies were methodologically flawed. The judgements of parental adequacy were limited by being based simply on

the author's comparative impression of the "norm" rather than in any firm definition of parenting or as compared to control groups of parents without a learning disability. Most studies relied on indirect means of assessing parental competence such as case records, place of residence of child, or third party sources such as health care visitors. Dowdney & Skuse (1993) note that the criteria by which researchers have defined parental success has varied from physical care provided (Kaminer, Jedrysek & Soles, 1981, Mickleson, 1947, Shaw & Wright, 1960), whether agency support is required (Sally, 1973) to child outcome measures (Feldman et al., 1985, Gillberg & Geijer-Karsson, 1983, Whitman et al., 1989).

Some later studies have, however, employed direct observation of parenting skills and behaviour to assess parental adequacy (Crittenden & Bonvillian, 1984, Feldman, Towns, Betel, & Case et al., 1986, Peterson, Robinson & Littman, 1983). Crittenden & Bonvillian (1984) studied video-recordings of three-minute child play sessions of ten mothers with a learning disability. The diverse range of scores (from high sensitivity to neglect) led the authors to conclude that a characteristic pattern of mother-infant interaction for mothers with a learning disability did not exist. Dowdney & Skuse (1993) note that the generalisation of observational studies is questionable as parenting style has been deduced from brief play sessions, lasting at the most ten minutes.

#### **1.5.5. Is there a higher rate of abuse and neglect amongst parents with a learning disability?**

The evidence for the belief that most or all parents with a learning disability abuse or neglect their children this is very mixed. Some empirical evidence suggests parents

with a low IQ do not have sufficient parental competencies to deal with children with complex needs (e.g. special diets/medication) (Schilling & Schinke, 1984, Sinason, 1992). Taylor, Norman, Murphy & Jellinek et al. (1991) examined more than 200 court records of abuse and/or neglect and concluded that intellectual and emotional impairment among parents was a significant contributing factor. Parents of low intelligence were found to have children permanently removed more often than emotionally disordered parents. The authors suggest that this was due to parents being unable to make the court-order changes.

In 1995, (NACPC, 1995) agencies were invited to nominate cases where serious concerns about child neglect were present and parents were identified as vulnerable. Of the 15 cases nominated, the main perceived parent problem was a learning disability (53%). Shaw & Wright (1960) reported that of 197 parents with a learning disability, one-third were known to the NSPCC or had had their child removed.

Research suggests that intentional abuse by a mother with a learning disability is rare and where such abuse occurs it is often as a result of an emotionally disturbed or criminal partner (Koller & Richardson, 1988, Tymchuk, & Andron, 1990). Glaun & Brown (1999) studied 12 court records of child protection cases in which the mother had an intellectual disability. The authors concluded that rather than learning disability per se, the cumulative effect of limited intellectual resources with other stressful emotional, physical and social factors precipitated a crisis in childcare. This supports other research, suggesting that a lack of parenting skills in combination with necessary supports may be crucial factors in determining how adequately these mothers look after their children (Llewellyn, 1990, Tymchuk & Feldman, 1991). In

the absence of any parenting education or supports, prior abuse is a strong predictor of abuse in the future (Tymchuk & Andron, 1990).

#### **1.5.6. Do parents with a learning disability understimulate their children?**

It has been suggested that the most serious deficits of parenting by persons with a learning disability is their inability to provide a stimulating environment (e.g. Feldman et al., 1985, Schilling, Schinke, Blythe & Barth, 1982). A restricted style of parent-child interaction has been found to have a detrimental effect on the IQ of the child (Martin et al., 1990, Ramey & Campbell, 1984,) with risk for developmental delay occurring as early as two years of age (Feldman et al., 1985). Johnson & Clark (1984) found that the limited communication and learning skills of parents with a learning disability intensified parenting difficulties as their children matured. Cognitive disparity between parent and child resulted in problems of parental control and discipline. The parents' lack of problem solving skills resulted in impulsive overreaction to stressful parenting situations, often involving excessive controlling and restrictive parenting behaviour.

Contrary to this finding, Feldman et al. (1986) found mean scores for eight mothers with a learning disability on the Home Observation for Measurement of Environment (HOME, Caldwell & Bradley, 1984) to be virtually identical to the normative population. However, the scores on the maternal interaction subscale were substantially below the mean, showing that the mothers were more likely than the HOME normative to restrict their children's freedom and to use punishment.

### **1.5.7. Behavioural problems of children whose parents have a learning disability**

Most studies of children raised by parents with learning disabilities have focused on intellectual and language deficits (e.g. Feldman et al., 1985, Reed & Reed, 1965). Few studies have focused on behavioural adjustment. Studies reveal that parents with a learning disability may need more help to discipline their children than parents with any other type of impairment (Berkley Planning Associates, 1997). It has been reported that behavioural problems are common amongst children of parents with a learning disability, particularly amongst boys (Feldman & Walton-Allen, 1997) and with increasing susceptibility as they grow older (Accardo & Whitman, 1990). In an early study (Robinson & Robinson, 1976) it was found that even when parents with a learning disability have children of average intelligence, they tend to have high rates of academic and behavioural problems. Gillberg & Geijer-Karlsson (1983) conducted a 1 to 21 year follow up of 41 children born to intellectually disabled parents and found that 75% of them were registered for psychosocial problems. Studies have cited that around 50% of offspring of people with a learning disability have behavioural difficulties (Kaminer et al., 1981 O'Neill, 1985) and Gillberg & Geijer-Karlsson (1983) found that 58% of the children required psychiatric services.

A more recent study (Feldman & Walton-Allen, 1997) found that children (n=27) with mothers with a learning disability had lower IQ scores, academic achievement and behavioural problems. Not one child was problem-free, including the 40% of children in the average range of intelligence. Social support was lower in the learning disabled group and correlated negatively with child behavioural problems. As the

comparison group was similarly impoverished the authors suggested that the results could not have been attributed to poverty alone.

#### **1.5.8. General parenting difficulties experienced by parents with a learning disability**

Holburn, Perkins & Vietze (2001) suggested the parenting style of mothers with a learning disability varies as much as the parenting style of other mothers. Whilst being mindful of this, McGaw (1993) notes we should also be aware of the difficulties that are unique to this group and may directly affect their parental competency.

McGaw (1993) notes that parents with a learning disability may have particular difficulties with housekeeping, hygiene, neglect and home safety which on an everyday basis often means that minor difficulties can quickly escalate into major problems. Poor cognitive skills may lead to difficulty keeping appointments and following calendars, identifying and understanding the significance of symptoms of common childhood illnesses (Tymchuk, 1990c), understanding the developmental level of their child (McGaw, 2000) and recognising the potentially dangerous or risky situations within the home (Tymchuk, 1991). Tymchuk, Yokota & Rahbar (1990) did however find that mothers with a learning disability made decisions about familiar childcare problems (presented as vignettes) as least as well as those made by contrast mothers from similar backgrounds.

Llewellyn, McConnell, & Bye (1998) found that specialist service providers identified that parents with a learning disability needed to learn (1) more about child development and how children's needs change over time (2) how to stimulate child

development through play (3) how to discipline children and how to adjust discipline to fit different situations (4) how to recognise when children are at risk either from others or their own behaviour and how to set boundaries for their safety and (5) how to react to the challenges of adolescence.

#### **1.5.9. Child behaviour management skills of parents with a learning disability**

Parenting by mothers with a learning disability has been characterised as restrictive, unstimulating, low in frequency and limited in variety (Tymchuk et al., 1987, Tymchuk & Andron, 1988). McGaw (1993) notes that parents with a learning disability do not tend to reward or reinforce appropriate behaviours from their child. Andron & Tymchuk (1987) suggest this difficulty may be due to the little praise they themselves received as children.

Child protection workers have also reported a failure of parents with a learning disability to bond with their children (Haavik & Menninger, 1981). Crittenden & Bonvilian (1984) found that mothers with a learning disability showed little affection and observational studies have found these mothers to be less involved and sensitive in their play behaviour than comparison mothers (Feldman et al., 1986). They issued more commands, imitated their children less and gave less praise (Feldman et al., 1986, Peterson et al., 1983). Mothers with a learning disability with children in care (Quinton & Rutter, 1984) were found to be more insensitive and negative, demonstrating less warmth towards their children than a comparison group. The discipline attempts were frequently both ineffective and inconsistent. The mothers themselves had often experienced serious adverse family conditions in their own childhood and a significantly greater number than the control group had been taken

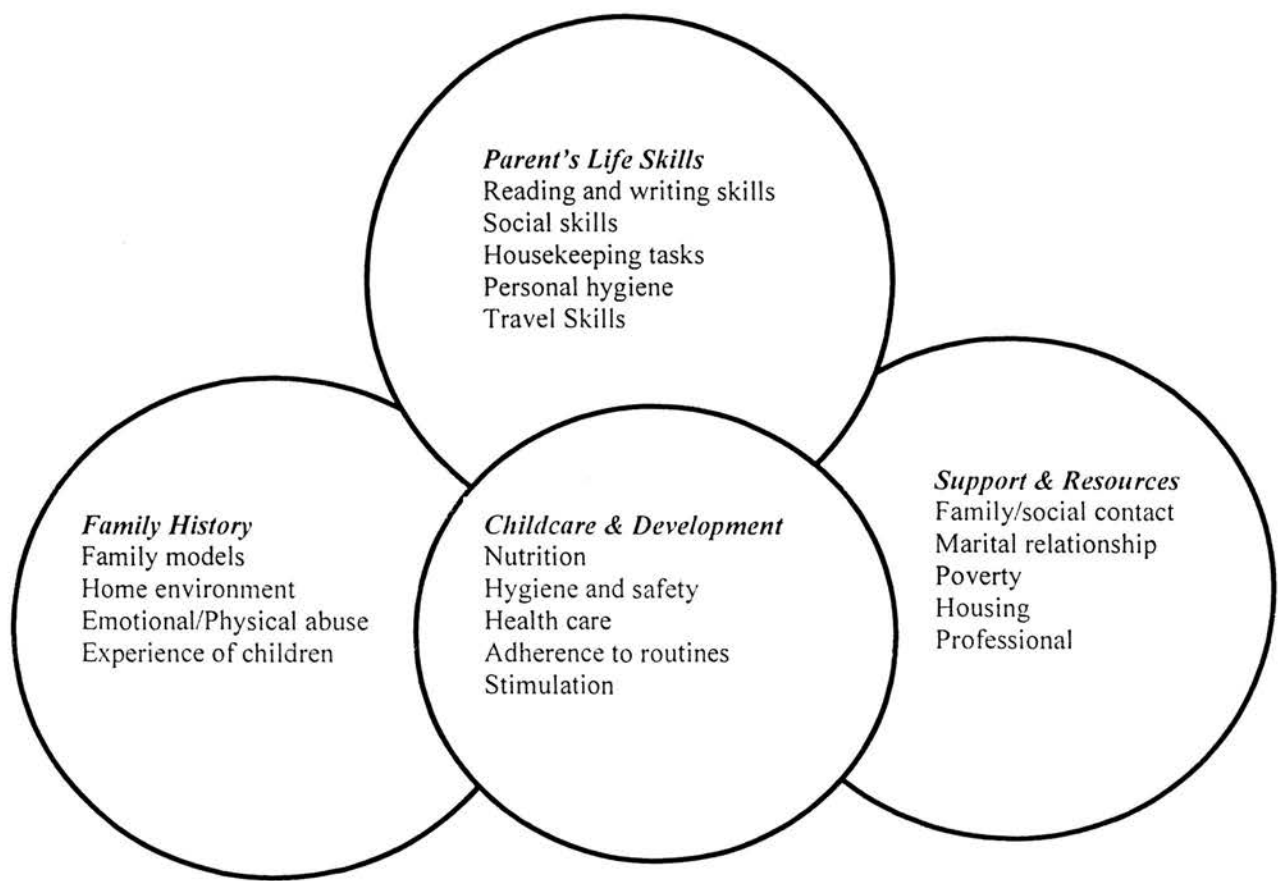
into care themselves. Dowdney, Skuse & Rutter et al.'s (1985) research, however, indicated that institutionalised upbringing alone did not result in a general emotional deficit.

Mira (1982, 1984) concluded that while in comparison to middle-class mothers, parents with a learning disability rarely praised, usually punished and had limited cognitive interactions with their children, parenting style did not differ when compared with parents of the same socio-economic group.

#### **1.5.10. Professional assessment of parental competency**

McGaw & Sturmey (1994) developed the Parental Skills Model (PSM) as an assessment guide of parental competency of parents with learning disabilities. They suggest adherence to the model ensures information is gathered in terms of the primary indicators (i.e. childcare and development) and secondary indicators (i.e. parent's life skills, family history and support/resources) of parental adequacy. The PSM model has been illustrated in figure 2.





**Figure 2:** Parental Skills Model (PSM)

#### 1.5.11. Summary

In summary, research fails to provide a definitive answer to the question of whether parents with a learning disability provide adequate parenting. The literature does support the concern that many parents with a learning disability have limited knowledge, poor understanding and inadequate skills in parenting. However, many parents with a learning disability can and do become good-enough parents especially if given support (Gath, 1988). Craft (1993) states that as a reference point we should hold on to two clear statements; (1) Having a learning disability does not necessarily

make a person an incompetent parent and (2) Not having a learning disability does not necessarily make a person a competent parent.

Parenting by persons with a learning disability is explored further in section 1.7, including a discussion of the major question posed in more recent literature reviews- if parents with a learning disability are found not to be parenting adequately, can they be taught to do so? (e.g. Dowdney & Skuse, 1993). Firstly, however, general parenting principles and programmes are introduced in section 1.6, including the most recently developed positive parenting programme, the Triple P, and the current focus on improving parental mental health through parenting interventions.

## **1.6 PARENT TRAINING PROGRAMMES**

### **1.6.1. Principles underlying parenting programmes**

The theoretical basis of parent training is rooted in Patterson's (1982) 'coercive family process hypothesis', which proposes that problem behaviours are unintentionally developed and maintained in the home by reinforcing contingencies. This hypothesis also drew on Bandura's (1977) social learning theory and proposed that, in addition, children learn to be aggressive by *modelling* parents' aggressive behaviour. Based on the theory that reducing coercive parenting interactions will decrease behavioural problems, the ultimate purpose of any parenting package is to reduce children's problem behaviour by strengthening parent management skills (Hartman, Stage & Webster-Stratton, 2003).

### **1.6.2. Parenting training programmes for the general population**

The pioneering work of Patterson and colleagues led to the design of behaviourally based training interventions for parents. The content of these included teaching parents how to record and reinforce behaviours, giving instructions effectively, discipline procedures and how to play non-directly with children (e.g. Forehand & McMahon, 1981, Patterson, Cobb & Ray, 1973). Following on from these programmes, Webster-Stratton (1981a,b, 1982a,b, 1984) developed a very influential videotape-modelling programme, which comprised of a parental model dealing both correctly and incorrectly with child misbehaviour.

Patterson et al. (1973), Forehand & McMahon (1981) and Webster-Stratton (1981a,b, 1982a,b, 1984) parenting programmes have been extensively evaluated. Significant positive changes in parent and child behaviour and in parental perceptions of child adjustment have been reported (McMahon & Forehand, 1984, Patterson et al., 1973, Spitzer, Webster-Stratton & Hollinsworth, 1991, Webster-Stratton, 1981, 1984, Webster-Stratton, Kolpacoff & Hollinsworth, 1988). Home observations have indicated that parents are successful in reducing children's level of aggression by 20 to 60 per cent (Patterson, 1982, Webster-Stratton, 1981b). The programmes have also had high parental ratings of acceptability and consumer satisfaction (Cross Calvert & McMahon, 1987, McMahon & Forehand, 1984, Webster-Stratton, 1989). The changes resulting from parenting programmes have been shown to be superior to family-based psychotherapy and no-treatment conditions. (Patterson, Chamberlain & Reid, 1982, Wells & Egan, 1988).

### **1.6.3. Parent training and mental health**

Evidence is beginning to emerge in showing that parenting groups can have a beneficial effect on child and adult mental health (Barlow, in press). Webster-Stratton's (1994) enhanced therapist-guided videotaped parent training programme has been reported to reduce maternal depression. McNamee, Lipman & Hicks (1995) ran a single mothers' group (an at-risk group for developing depression) for mothers of children attending a psychiatric clinic. Participation in the support group resulted in a significant decrease in depression and increase in self-esteem. Sanford, Byrne & Williams et al. (2003) evaluated a parent-education group for families affected by depression and found medium effect sizes although the drop-out rate was 27% by post-treatment and 43% by follow-up. Patterson, Barlow, Mockford, Klimes, Pyper & Stewart-Brown (2002) found the Webster-Stratton parenting programme was effective for improving some aspects of children's mental health (notably conduct problems). Parental scores also significantly improved on the Parenting Stress Index (Abidin, 1995), indicating a decrease in parental stress levels.

Barlow, Coren & Stewart-Brown (2002) carried out a meta-analysis of the effectiveness of parenting programmes in improving maternal psychosocial health. A review of fifteen controlled studies showed statistically significant results favouring the intervention group for depression, stress, self-esteem and relationship with partner. The meta-analysis of social support data showed no evidence of effectiveness.

Patterson et al. (2002) propose that parenting groups can make a useful contribution to the national NHS priority of mental health promotion in Primary Care. It has been

proposed that the Triple P positive parenting programme is an example of a population-level strategy to improve the mental health status of children and parents (Sanders, 1999). There appears to be no studies, however, which have looked at the effect of intervention on the mental health of parents with a learning disability.

#### **1.6.4. Positive Parenting Programme (Sanders, 1999)**

The Positive Parenting Programme (Triple P, Sanders, 1999) aims to prevent severe behavioural, emotional and developmental problems in children by enhancing the knowledge, skills and confidence of parents. The programme recognises that parents have differing needs and desires regarding the type, intensity and mode of assistance they may require and therefore five levels of intervention are available. These are illustrated in figure 3.

#### **1.6.5. Is Triple P effective?**

Triple P evolved from a programme of clinical research (Sanders, 1996, 1999, Sanders, Markie-Dadds, Tully & Bor, 2000). The parent training methods employed have been shown to be effective in reducing children's disruptive behaviour in a variety of populations, including children from homes with marital problems (Dadds, Schwartz & Sanders, 1987), children of depressed parents (Sanders & McFarland, 2000) and children in step-families (Nicholson & Sanders, 1999). Zubrick, Silburn, Garton, Burton, Dalby et al. (2001) conducted the largest reported evaluation of parent training using the Triple P. The children of 718 parents who participated in Triple P showed a significant reduction in levels of disruptive behaviour and lower levels of coercive parenting than the 806 parents who did not receive any training. There were also significant improvements in parent-reported depression, anxiety and

Level of intervention	Target population	Intervention methods
<b>1. Universal Triple P</b>  Media-based parenting information campaign	All parents interested in information about parenting and promoting child's development	A coordinated information campaign using print and electronic media and other health promotion strategies to promote awareness of parenting issues and normalise participation in parenting programmes such as Triple P. May include some contact with professional staff (e.g. telephone information line)
<b>1. Selected Triple P</b>  Information and advice for a specific parenting concern	Parents with specific concerns about their child's behaviour or development	Provision of specific advice on how to solve common child development issues and minor child behaviour problems. May involve face-to-face or telephone contact with a practitioner (about 20 minutes over two sessions) or 60-90 minute seminars
<b>2. Primary Care Triple P</b>  Narrow focus parenting skills training	Parents with specific concerns about their child's behaviour or development who require consultations or active skills training	A brief programme (about 80 minutes over four sessions) combining advice with rehearsal and self-evaluation as required to each parent to manage a discrete child problem behaviour. May involve face-to-face or telephone contact with a practitioner.
<b>3. Standard Triple P</b> Group Triple P Self-Directed Triple P  Broad focus parenting skills training	Parents wanting intensive training in positive parenting skills. Typically targets parents of children with more severe behaviour problems	A broad focus (about 10 hours over 8-10 sessions) for parents requiring intensive training in positive parenting skills and generalisation enhancement strategies. Application of parenting skills to a broad range of target behaviours, settings and children. Programme variants include individual, group or self-directed (with or without telephone assistance) options
<b>4. Enhanced Triple P</b>  Behavioural family intervention	Parents of children with concurrent child behaviour problems and family dysfunction	An intensive individually tailored programme (up to 12 one hour sessions) for families with child behaviour problems and family dysfunction. Programme modules include practice sessions to enhance parenting skills, mood management strategies, stress coping skills and partner support skills.

**Figure 3:** The Triple P model of Parenting and Family Support

stress, improved marital adjustment and conflict over child rearing. A large majority (89%) rated the programme as either excellent or very good.

Despite the breadth of empirical evaluation of parenting packages, none of these packages have been evaluated on parents with a learning disability, which section 1.7 addresses further.

#### **1.6.6. Summary**

Parent training programmes have been found to be effective in improving parental skills and more recently mental health gains have been demonstrated by participation in these programmes. The most recently developed parenting programme, the Triple P, has undergone considerable empirical evaluation although it has not been evaluated on parents with a learning disability.

### **1.7. PARENT TRAINING WITH PARENTS WITH A LEARNING DISABILITY**

The following section reviews the literature on parenting training programmes for parents with a learning disability and highlights issues with inadequate service provision, assessments and materials for this parenting population.

#### **1.7.1. Lack of provision for parents with a learning disability**

The majority of global parenting programs available within the UK are aimed at the general parent population with no adaptation for parents with a learning disability (Feldman et al., 1986, Peterson et al., 1983). Surveys of group-based parenting programs reveal that very few organisations acknowledge or attempt to identify

parents with a learning disability within their parent population (Grimshaw & McGuire, 1998, Smith, 1996).

### **1.7.2. Inclusion in general parenting programmes?**

McGaw (1994) comments that those parents with a learning disability who do attend group programs can be at risk of rejection from other parents. Parents with a learning disability may appear 'different' due to a congenital abnormality and experience difficulty communicating due to poor social skills and low self-esteem. Staff running the groups may expect unrealistic levels of skill in reading, numeracy and time-keeping. Peterson et al. (1983) note that parenting programmes seem designed for highly educated parents in that they stress cognitive concepts, require extensive reading, record keeping and application of abstract psychological principles. Johnson & Clark (1986) found that many service providers were frequently unwilling to adjust their communications for parents with a learning disability. Research indicates that parents with a learning disability do not benefit from participating in a group with non-disabled parents and may need their own groups, which include practical activities (Llewellyn, 1994). McGaw (2000) notes that when groups are tailored to the needs of parents with a learning disability they can be a powerful method for change.

### **1.7.3. Can parents with a learning disability benefit from parent training?**

#### **1.7.3. (a) Training in general childcare skills**

Feldman (1994) reviewed 20 suitable outcome studies relating to the impact of parental training programmes and concluded that 96% of the 190 parents in the studies (188 mothers, 2 fathers) showed improvements in one or more skills and



improvements were noted in 63% of the skills addressed in training (e.g. basic childcare, safety, nutrition, problem-solving, positive parent-child interactions). The most common teaching approaches used were behavioural (e.g. task analysis, modelling, feed-back, reinforcement). A weakness in generalisation and child-outcome data were highlighted and the fact that the majority of 'parenting' studies only included mothers (and not fathers) with a learning disability.

Interventions aimed at teaching mothers to recognise and respond appropriately to home danger situations and implement safety precautions have reported positive results (Feldman, 1986), as have child illness symptom recognition, understanding and treatment (Tymchuk, 1990c), training in household routines (Whitman et al., 1989), use of both prescription and over-the-counter medications (Tymchuk, 1999), use of high-risk household products (Tymchuk et al., 1990), basic childcare skills such as bathing & cleaning bottles (Feldman, Case, Garrick, Macintyre-Grande, Carnell, 1992) and nutritional advice (Sarber, Halasz, Messmer, Bickett & Lutzker, 1983). Performance-based methods (e.g. modelling, role-play, picture-cards, check-lists) tended to be used in these studies. Tymchuk, Andron & Rahbar (1988) found that parents with a learning disability could be trained to learn and generalise five of six steps involved in decision making about high-risk child problems. Fantuzzo, Wray, Hall, Goins & Azar (1986) also found that as a result of training, mothers with a learning disability and a history of maltreatment improved their ability to identify the most appropriate action in response to child problems. Feldman et al. (1992) suggest parent training is a satisfactory alternative to the removal of a child from the home when parenting skills deficits place the well being of the child in jeopardy.

### **1.7.3. (b) Training in positive parent-child interactions**

Using play sessions, Peterson et al. (1983) succeeded in teaching six parents with a learning disability (IQ range 59-73) how to describe, praise, reflect and interact non-directly with children using modelling, role-playing and coached practice. While generalisation was not formally assessed, anecdotal reports from the health visitors suggested that about half were inconsistent employing the skills learned in the training. Fantuzzo et al. (1986) used a board game as a parent-training method for three mothers with a learning disability (IQ range 54-60) with confirmed cases of neglect. The game consisted of 24 situation cards e.g. 'you tell your child not to play with the ball in the house but he keeps bouncing the ball, what would you do?' (p. 136). Training in the correct response to the cards resulted in an increase in correct responses from 50% to 92%, although this may be due to simple rote-learning. In addition, as a control group was not employed and the game has no norms, it is difficult to know if parents without a learning disability would have scored any differently at baseline.

Feldman et al. (1986) compared the interactions of eight mothers with low IQ (IQ range 59-77) with a non learning disabled comparison group during play with their young infants. After receiving a training package consisting of discussion, modelling, feedback, social reinforcement and self-recording the parents with a learning disability approximated the middle-class mothers in terms of empathy, warmth and child interactions. Effects were generalised from the group to the home setting and were maintained for several months.

Similar results were found by Feldman, Case, Rincover, Towns & Betel (1989). Physical affection and praise of three mothers with a mild learning disability (IQ range 61-79) increased after training to comparison levels (mothers without a learning disability) and were maintained for a 3 to 18 month follow-up period. Teaching the parents to imitate child vocalisations was related to gains in the frequency and quality of the verbal behaviour of two language-delayed children. Tymchuk & Andron (1988) also found that training of two mothers with a learning disability resulted in a reduction of physical punishment and an increase in praise. However, there was little improvement in spontaneous positive affect and a persisting lack of ability to apply rules flexibly to meet their children's developmental needs.

Tymchuk, Andron & Tymchuk (1990) trained eight mothers with a learning disability to understand and apply behavioural and developmental principles. The outcome measures were devised by the authors and comprised of a verbal questionnaire (e.g. 'what is wrong with hitting your child?') and two visual questionnaires where mothers responded to illustrations of child adaptive and maladaptive behaviours. Significant differences were only found on the verbal questionnaire. Both sets of parents chose reprimanding as a strategy for misbehaving rather than ignoring. The authors suggested that mothers with a learning disability did not seem to know *how* to reinforce or *what* to reinforce. After training (two ninety minute sessions on the correct responses to the questionnaire) there was no difference between the groups on the verbal questionnaire. As with Fantuzzo et al.'s (1986) study, simply training correct responses to a board game or questionnaire would appear to be limited in terms of 'parent training' and results in increased knowledge in relation to a set of specific questions, rather than parenting skills per se.

Using video-tape recordings of mother-child interactions Tymchuk & Andron (1992) increased the use of praise in nine mothers with a learning disability (IQ range 58-72). The authors highlighted that *neither* the learning disabled or control group engaged in verbal or physical punishment and *both* sets of mothers also had difficulty recognising and encouraging prosocial behaviour in their children. The authors note that several of the mothers with a learning disability were slow to learn and lost their gains after a month's follow-up.

While researchers have consistently found that praise is the single most lacking behaviour of parents with a learning disability, many of the parents in the studies exhibited behaviours considered to be a prerequisite of adequate parenting (Feldman et al., 1986, Peterson et al., 1983, Tymchuk & Andron, 1992).

#### **1.7.4. Methodological limitations of parent-training research for people with a learning disability**

Many of the above studies have relied on the "social systems" (Mercer, 1973), definition of learning disability; that is, persons with an IQ of less than 80 with a history of educational and practical support. The IQ cut-off of 80 is problematic as this does not meet commonly accepted criteria for a learning disability (AAMR, 1992, BPS, 1991) i.e. IQ<69). Furthermore, in some of these papers IQ's are missing for some participants (e.g. Peterson et al., 1983) and is simply based on, for example, a history of special needs schooling. Where IQ is stated, the method of measurement is often not included (e.g. Feldman et al., 1989). The diagnosis of mild to moderate learning disability in Llewellyn et al. (1999) was simply based on the opinion of the 'experienced' investigators.

In terms of method of assessment the majority of papers have used short observational assessment during five to ten-minute play sessions (e.g. Feldman et al., 1986, 1989, Peterson et al., 1983) or even three-minute play sessions (Cittenden & Bonvilliam, 1984). In terms of the interventions used, only one paper (i.e. Peterson et al., 1983) employed a structured and empirically evaluated parenting programme (i.e. Hanf & Kling's (1974) Parent-Child Interactional Training). The location of training was inconsistent in Feldman et al.'s (1986) study as some parents were trained at home, some in a group and some at both. The details of the training are very generally described and training received by the home participants was described as 'similar to that provided in the group' (p. 29). To make general conclusions about the effects of parent training in this paper would appear to be problematic given the number of variables involved.

Tymchuk & Andron (1992) note that methodological problems of the Peterson et al. (1983) and Feldman et al. (1986, 1989) studies include inconsistent treatment of the mothers, modification of the definition of praise throughout the studies, lack of sufficient demographic data to compare findings and the use of middle-class contrast groups. Previous papers have also tended to restrict their focus to increasing positive play, praise and affection with young children, ranging from 6 month old babies (Feldman et al., 1986) to an upper age of five (e.g. Peterson et al., 1983) which tells little about the parenting of older children and adolescents by people with a learning disability.

### **1.7.5. Assessing the emotions of people with a learning disability**

Although none of the reviewed parenting studies assessed parental mental health, research has moved towards more reliable and systematic ways of asking clients with learning disability to report on their private world. Lindsay & Michie (1988) and Michie and Lindsay (1988) found that standard presentations of the Zung scales (1965, 1971) assessing anxiety and depression in adult populations produced very low reliability scores. By redesigning the test (i.e. simpler language and scoring) reliable scores were produced for clients with a learning disability. Furthermore, Kazdin, Matson & Senatore (1983) found that people with a learning disability could reliably respond using the multiple-choice format in the Zung scales when accompanied by a bar graph to represent the choices. Lindsay (1991) concluded that if care is taken, it is possible to conduct reliable and valid assessments of the private feelings and thoughts of people with a learning disability.

The Glasgow Depression and Anxiety scales (Cuthill et al., 2003, Mindham & Espie, 2003) for people with a learning disability (Cuthill et al., 2003) utilises a two-stage means of responding to reduce perseveration and acquiescence (Flynn, 1986). Initially respondents are required to give a yes/no answer (assisted by a large tick and cross) to simply indicate presence or absence of a symptom. If a 'yes' response is given, the person is asked to indicate severity of the symptom using different sized 'puddles' representing 'never' 'sometimes' or 'a lot'.

#### **1.7.6. Guidelines for parenting skills training with parents with a learning disability and available materials**

There is a particular absence of carefully evaluated and easily replicated programmes for teaching parenting skills to parents with a learning disability (Budd & Greenspan, 1984, Foxx, McMorow & Schloss, 1983, Murphy, 1996). Researchers have, however, provided some general guidelines for running parenting programmes for parents with a learning disability;

- training should be set at the right level of comprehension and understanding and avoid abstract instructions (Green & Vetere, 2002, Shearer & Shearer, 1976). Peterson et al. (1983) minimised record-keeping and emphasised concrete behaviour rather than abstract principles;
- training methods should not be solely verbal in nature and need to be based on task analysis, repetition, modelling, guided practice and the use of positive contingencies to reinforce learning (Feldman, 1994, Feldman et al., 1986, Peterson et al., 1983);
- written instructions should reflect the reading age of parents (on average around the seven to nine year age level) and be presented in uncluttered print (Tymchuk, 1990b). Shearer & Shearer (1979) adapted the Portage parent training programme for parents with a learning disability by simplifying the materials, increasing the frequency of teaching sessions and using pictorial instructions. McGaw (2000) recommends providing parents with a dictionary of commonly used words of terms, accompanied by symbols;

- the intervention should match the characteristics of the mother (Tymchuk, 1992); and
- the facilitators should be consistent, adequately trained and have open attitudes towards the abilities of the participants (Tymchuk, 1992).

### **1.7.7. Summary**

The research reviewed above has shown that parents with a learning disability can be taught to increase positive parent-child interactions, domestic skills, decision-making skills, problem solving skills and child behaviour management skills (Budd & Greenspan, 1984, Feldman, 1986, Haavik & Menninger, 1981, Kaminer, Jedrysek & Soles, 1981, Murphy, Coleman & Abel, 1984, Tymchuk & Feldman, 1991). The research does however suggest that parents with a learning disability do not benefit from participating in mainstream parenting groups and require their own specific groups where efforts have been made to adapt content and teaching methods.

## **1.8. AIMS AND HYPOTHESES OF THE PRESENT STUDY**

### **1.8.1. PART A (“The Social and Emotional Lives of Parents with a Learning Disability”) – Research aims**

Stenfert-Kroese et al. (2002) noted that ‘very little is known about the psychological well-being of parents with intellectual disabilities’ (p. 326) and the overview given above indicates that research conducted with parents has often excluded parents with a learning disability. The first part of this study aims to examine neglected areas of investigation with parents with a learning disability, that is (1) parental stress (2) anxiety and depression (3) behavioural problems of children (4) the support networks of these parents and (5) parental behaviour management skills. In addition, the study



aims to assess how the levels of parent and child mental health compare with a group of parents without a learning disability referred to a local Clinical Psychology Department for parenting difficulties. The study also aims to investigate both type and perceived quality of social support by parents with a learning disability. The hypotheses for this part of the study are, therefore, as follows:

#### **1.8.2. Part A – Research questions and hypotheses**

**Research question A1:** What levels of parental stress are the parents with a learning disability experiencing?

**Hypothesis A1:** The parents with a learning disability will be experiencing high levels of parental stress and levels greater than the control group.

**Research question A2:** Are the parents with a learning disability experiencing difficulties with anxiety and depression?

**Hypothesis A2:** The parents with a learning disability will be experiencing high levels of anxiety and depression and of a greater severity than the control group.

**Research question A3:** Are the parents with a learning disability experiencing difficulties with child behaviour?

**Hypothesis A3:** The children of parents with a learning disability will have a high number of behavioural difficulties and more difficulties than the control group.

**Research question A4:** How many social supports do the parents with a learning disability have access to and are they satisfied with this support?

**Hypothesis A4:** The parents with a learning disability will have lower levels of social support than the control group and be less satisfied with these supports.

**Research question A5:** Which parenting strategies do parents with a learning disability use?

**Hypothesis A5:** The parents with a learning disability will show low levels of praise and high levels of ineffective punitive parenting techniques.

### **1.8.3. PART B (“The impact of a positive parenting programme on psychological well-being”) – Research aims**

The second part of the study aims to investigate whether a Positive Parenting Programme (Triple P, Sanders, 1999) set-up and adapted specifically for parents with a learning disability will be effective in terms of improving (1) parental stress (2) anxiety and depression (3) child functioning, (4) social support and (5) parental skills as measured in Part A of the study. An aim of this second part of the study is also to assess parental satisfaction with the adapted Triple P programme. This is consistent with Feldman’s (1994) recommendation that ‘more data is required in the effectiveness of learning disabled parent education with regard to...collateral effects such as parental stress...the benefits to the child ...and validation measures such as consumer satisfaction’ (p. 328). Feldman (1986) notes that it is important to establish

training results in terms of clinical validity (by assessing effects on child behaviour) and social validity (by comparing the results with a non learning disabled population) both of which have been carried out in this study.

#### **1.8.4. Part B – Research questions and hypotheses**

**Research question B1:** Does a positive parenting group for parents with a learning disability have a beneficial effect on parental stress?

**Research question B2:** Does a positive parenting group for parents with a learning disability have a beneficial effect on anxiety and depression?

**Research question B3:** Does a positive parenting group for parents with a learning disability have a beneficial effect on child behaviour?

**Research question B4:** Does a positive parenting group for parents with a learning disability have a beneficial effect on social support?

**Research question B5:** Does a positive parenting group for parents with a learning disability have a beneficial effect on parental skills?

**Research question B6:** What is the level of consumer satisfaction with a positive parenting group for parents with a learning disability?

#### **1.8.4. (c) Consideration of hypotheses to Part B research questions**

It is very difficult to make clear hypotheses about the effect of Triple P on the above factors as this is a pilot study and no literature exists which has examined the effect of the Triple P programme with parents with a learning disability, despite its wealth of scientific investigations on other populations. An aim of Triple P is to reduce parental stress by teaching coping strategies, building positive relationships with children and taking care of themselves as a parent, which may allow us to make the following hypotheses:

**Hypothesis B1:** The positive parenting group for parents with a learning disability will reduce parental stress.

**Hypothesis B2:** The positive parenting group for parents with a learning disability will improve levels of anxiety and depression.

**Hypothesis B3:** The positive parenting group for parents with a learning disability will result in a decrease in child behaviour scores.

**Hypothesis B4:** The positive parenting group for parents with a learning disability will increase social support scores and perceived helpfulness of supports.

**Hypothesis B5:** The positive parenting group for parents with a learning disability will increase levels of praise and effective child behaviour management strategies.

**Hypothesis B6:** Parents with learning disabilities will report high levels of satisfaction with the group.

## **CHAPTER TWO**

### **METHOD**

## 2. 1. RECRUITMENT PROCEDURE

### 2.1.1. Parents with a learning disability

A discussion with several Learning Disability Community Nurses (CLDN) and Health Visitors revealed that many of them were working with parents with a learning disability and agreed there was a need for parenting group(s) to be held in the area. Having obtained ethical approval from the Local Committee on Medical Research Ethics (Appendix 1), a letter explaining the research, inclusion criteria, content of the positive parenting group and referral form (Appendix 2) was sent to learning disability and child health and social work professionals across Tayside, as detailed in table 1.

Professional receiving information about the group	Number sent
<b>Learning Disability Services:</b>	
Community Nurses	24
Care Managers	27
Psychiatrists	3
Psychologists	5
<b>Child &amp; Family Services:</b>	
Psychiatry	29
Psychology	4
Senior Social Workers	12 *
<b>Health Visitors</b>	126
<b>Total</b>	<b>230</b>

\* Distribution unknown as distributed via senior social workers to other staff

*Table 1: Distribution of information about group and request for referrals*

The health professionals were asked to inform any parents with a learning disability with whom they were working about the study. They then gave them or read to them the Parent Information Booklet (Appendix 3). If the parent expressed an interest in participating in the study, the professional was asked to complete the referral form, which included a space for the parent to provide a signature to assure consent had been given for their name and address to be given to the researcher.

The Child & Adolescent Clinical Psychology waiting list was also examined to identify parents with a learning disability referred for parenting issues. The referrer was then asked to approach the parent as per the above procedure.

### **2.1.2. Consent issues**

A two-stage consent process was adopted. Having consented to their name and address being sent to the researcher by a trusted professional, on meeting the researcher the issue of consent was re-iterated and the parent was asked to sign a consent form devised for the parents with a learning disability by the researcher (Appendix 4). It was stressed that signing the consent form for the study did not mean they had to attend the parenting group. Parents were invited to ask questions about the group before signing the form. The assessment session allowed the researcher to assess suitability for the group based on the inclusion and exclusion criteria below:

## **2.2. INCLUSION AND EXCLUSION CRITERIA**

### **2.2.1 Inclusion Criteria**

The inclusion criteria for the study were

- an IQ between 60 and 75 i.e. mild learning disability or borderline intellectual functioning (This IQ range was selected as it was similar to IQ inclusion criteria of published research to allow comparability of the findings and was unlikely to cause problems with informed consent); and
- caring either full or part-time for a child under the age of 16 and with difficulties in managing the child's behaviour.



### 2.2.2. Exclusion Criteria

The exclusion criteria were

- referrals where needs were centred around domestic, safety, nutritional or physical childcare needs (e.g. changing nappies);
- parents' with an uncontrolled mental illness which was likely to disrupt group participation; and
- those involved in current childcare court cases or proceedings.

## 2.3. PARTICIPANTS

### 2.3.1. Referrals received for parents with a learning disability

Twenty-four referrals of parents with a learning disability (GROUP 1: LEARNING DISABILITY) were received for the study (23 mothers, one father). Three participants did not attend their assessment appointment on at least two occasions and were discharged from the project. One participant withdrew from the project before being offered an appointment and two mothers and a father were excluded due to a full scale IQ > 75 which was out-with the range of learning disabilities and hence the inclusion criteria. Eighteen sets of data (all mothers) were, therefore, collected for PART A of the study. The source of the 24 referrals has been illustrated in table 2.

Profession	Number of referrals received
Community Learning Disability Nursing	13
Health Visitors	6
Psychiatry	1
Care Management	3
School & Family Support Worker	1
Waiting List	1
<b>Total</b>	<b>24</b>

*Table 2: Source of referrals of parents with a learning disability*

Of the 18 mothers assessed in PART A, 11 attended at least one of the Triple P groups. Two parents attended only one session, three had other commitments at the same time as the group, one moved away, two did not attend for unknown reasons and one was seen individually due to location and inability to travel to the groups. Nine of the mothers attended the groups on at least three occasions enabling n=9 sets of data for PART B of the study. Six of these parents attended a six-week follow-up assessment session.

The location of referrals allowed three parenting groups for learning disabilities to be run across Tayside.

### **2.3.2. Clinical sample of parents without a learning disability**

This group consisted of 140 families who were on the local Child Clinical Psychology Department waiting list for help with parenting (parents without learning disabilities, GROUP 2: NON LEARNING DISABILITY). These parents were referred because of difficulties in managing the behaviour of their children. All of the 140 families were sent a letter indicating an option of joining a parenting group. Forty-five families wished to be offered a place on the next available parenting group. Of these 45 families, 22 attended (21 mothers, 1 father). Unfortunately only 8 of these 22 parents continued to attend the groups (all mothers), which enabled only a small sample of pre and post measures to be evaluated.

Additional pre-group control data (n=8) was made available from the Child Clinical Psychology Department for parents referred for inclusion in a parenting group, enabling n=30 control data for PART A of the study. Follow-up data was not

available, as parenting groups had ceased to be run by the clinical psychology department due to liaison with a voluntary service (Parent-to-Parent), who had agreed to take referrals from clinical psychology for parenting groups. The control data for PART B, therefore, remained at n=8. As all the 30 parents had been discharged before the groups for parents with a learning disability took place, six-week follow-up data was not collected and therefore only available for the parents with a learning disability.

Permission to use the control group data for research purposes was granted by the Tayside Caldicott Guardian (Appendix 5).

### **2.3.3. Demographic information**

Demographic characteristics of the participants has been presented in table 3 for PART A and table 4 for PART B, which also includes the mean number of Triple P sessions attended. As can be seen from Table 3 the IQ of the learning disabled sample ranged from 54-75. As the initial inclusion criteria was an IQ of 60-75, permission was granted from Tayside Ethics Committee to widen the inclusion criteria to 54-75 (Appendix 6) as the three parents with IQ<60 were very keen to participate and no problems had arisen with ability to consent.

	<b>Learning Disability Mean (SD) (n=18)</b>	<b>Minimum-Maximum</b>	<b>Non learning Disability Mean (SD) (n=30)</b>	<b>Minimum-Maximum</b>
<b>IQ</b>	65.3(5.38 )	54-75	unknown	unknown
<b>Parent Age (yrs)</b>	33.8 (6.55)	22-44	32.9 (4.69)	25-42
<b>No. of children</b>	2.8 (1.46)	1-6	2.4 (1.16)	1-5
<b>Child age (yrs)</b>	7.6 (3.27)	2-14	7.7 (2.53)	3-13
<b>% Employed</b>	0	N/A	46.7	N/A
<b>DEPCAT score<sup>1</sup></b>	4.9 (1.59)	1-6	3.9 (1.27)	2-5
<b>Living arrangements</b>				
% single	44.4	N/A	53.3	N/A
% married	22.2		40	
% partner	11.1		6.7	
% parents	16.7		0	
% supported accommodation	5.5		0	

*Table 3: Demographic information for parents of PART A of the study*

	<b>Learning Disability Mean (SD) (n=9)</b>	<b>Minimum-Maximum</b>	<b>Non learning Disability Mean (SD) (n=8)</b>	<b>Minimum-Maximum</b>
<b>IQ</b>	65.7 (4.33)	58-73	unknown	unknown
<b>Parent Age (yrs)</b>	35.9 (6.53)	27-44	36.5 (4.03)	30-42
<b>No. of children</b>	2.8 (1.20)	1-5	1.7 (0.89)	1-3
<b>Child age (yrs)</b>	8.9 (3.08)	3-13	7.6 (2.20)	4-11
<b>% Employed</b>	0	N/A	62.5	N/A
<b>DEPCAT score<sup>2</sup></b>	4.3 (1.87)	1-6	3.7 (1.39)	2-5
<b>Living arrangements</b>				
% single	66.7	N/A	50.0	N/A
% married	22.2		37.5	
% partner	0		12.5	
% parents	11.1		0	
% supported accommodation				
<b>Mean No. of Triple P sessions attended (max=5)</b>	4.1	3-5	2.5	3.9

*Table 4: Demographic information for parents of PART B of the study*

<sup>1,2</sup> Socio-economic status examined by means of the Carstairs Scores for Scottish Postcode Sectors (Public Health Research Unit, 2000). Based on house postcode, a deprivation category (DEPCAT) score is assigned, from 1 (most affluent socio-economic area) to 7 (most deprived).

## **2.4 PROCEDURE & DESIGN**

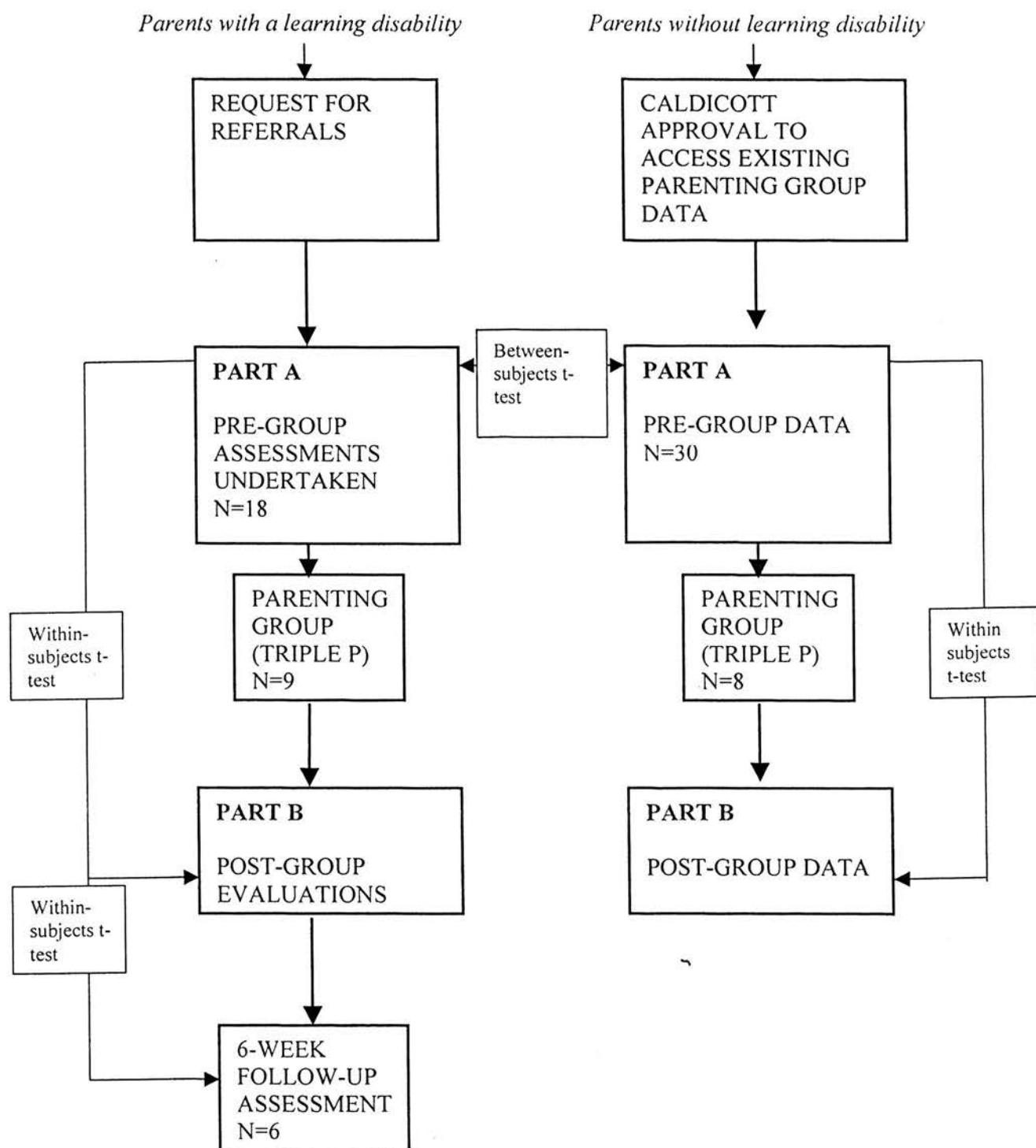
### **2.4.1. PART A**

On receiving a referral to the study the parent with a learning disability was interviewed to complete the assessments, confirm consent and if necessary, administer a cognitive assessment. PART A of the study, therefore, included a between-subjects exploration of (a) parental stress (b) anxiety and depression (c) child adjustment and (d) social support. The parenting skills assessment (e) was only completed with the parents with a learning disability.

### **2.4.2. PART B**

The eligible parents were invited to one of three positive parenting groups. The aim of the intervention was to examine within-group effects of treatment for both the parenting groups (i.e. with and without learning disabilities) on the multiple dependent variables i.e. (a) parental stress (b) anxiety and depression and (c) child adjustment. Pre-post data for social support (d) and the parenting skills assessment (e) was only available as a within-subjects measurement for the parents with learning disabilities. A between-subjects analysis was undertaken of consumer satisfaction (f) with the intervention. Six-week follow-up assessments were also administered with the parents with learning disabilities.

The procedure and design of the study is illustrated in figure 4.



**Figure 4:** Research study procedure and design

## **2.5. COGNITIVE ASSESSMENT & OUTCOME MEASURES**

### **2.5.1. Wechsler Abbreviated Scale of Intelligence (WASI, The Psychological Corporation, 1999)**

The WASI was used to establish IQ where a previous cognitive assessment had not been undertaken. The WASI is nationally standardised and was designed for a quick and accurate estimation of intellectual functioning. Included in its recommendations of use is 'obtaining estimates of IQ scores for research purposes, such as pre-experimental matching of cognitive ability'. Research has shown a full-scale correlation of .87 with the Wechsler Adult Intelligence Scale – III (WAIS-III). A study on 119 individuals with a learning disability suggested the WASI has 'sufficient sensitivity for screening for mental retardation' (The Psychological Corporation, 1999)

### **2.5.2. Family Background Questionnaire**

Both the control group and group of parents with a learning disability completed a Family Background Questionnaire prior to the intervention (Appendix 7a and 7b respectively). The Clinical Psychologist who ran the parenting groups in the department devised the control group questionnaire. The questionnaire for the participants with a learning disability also included relevant issues for this group such as history of institutionalisation/care.

### **2.5.3. Parenting Stress Index- Short Form (PSI/SF Abidin, 1995)**

The Parental Stress Index (PSI) measures the magnitude of stress in the parent-child system. The 36-item short-form was developed at the request of clinicians and

researchers for a valid measure of parental stress that could be administered in less than ten minutes. Castaldi (1988) factor-analysed the full length PSI and found that a short form generating a total stress score and three subscales (i.e. parental distress, parent-child dysfunctional interaction and difficult child) were psychometrically feasible. The theoretical model for the PSI/SF is included in Appendix 8a. The authors note that a primary category for use is for pre-post measurement of intervention effectiveness, as is employed in this study.

The participant is presented with a number of statements and asked to respond to each item with strongly agree (SA), agree (A), not sure (NS), disagree (D) or strongly disagree (SD), with the exception of item 22 and 32 which require a rating on a five point scale. Item 33 also differs in that the parent is required to count the number of things their child does that bothers them from 1 to 10. Lindsay (1991) recommends that 'with clients who have a mental handicap it is best to use a bar graph as a visual aid to help describe each answer point' (p. 227) and therefore bar graphs were provided for items 22, 32 and 33. The two-part scoring format of the Glasgow Depression Scale (Cuthill et al., 2003, see section 1.7.5.) was utilised to aid the parents with learning disabilities with the SA, A, NS, D and SD responses. Participants were required to initially answer 'yes' or 'no' to the items by pointing to a laminated card including a green tick or a red cross (they could also choose the 'not sure' response by pointing to the tick and cross together). If the parent chose 'yes' they were then asked to indicate if they strongly agreed with the item (by pointing to a big tick) or just agreed (pointing to a smaller tick). If the parent chose 'no' they were asked to indicate if they strongly disagreed (big cross) or just disagreed (little cross).



Percentile scores are used to interpret performance and in general, the normal range for scores is within the 15<sup>th</sup> to 80<sup>th</sup> percentile. Scores above the 90<sup>th</sup> percentile indicate clinically significant levels of stress. The parent is given a total stress score, which is derived from the total of the three subscale scores (parental distress, parent-child dysfunctional interaction and difficult child). In addition, a defensive responding score is calculated which is not included in the calculation of total stress. This score assesses the extent to which the parent is trying to give the most favourable impression of him/herself and to minimize indications of problems or stress. The short form PSI has sound test-retest reliability (.91) and concurrent validity (.94) with the long-form PSI (Abidin, 1995). While norms based on a sample of n=600 (Abidin, 1995) exist for the long-form version, this study has not been conducted on the short form. The cut-off scores for the domains and corresponding percentiles required for clinical significance have been presented in table 5, as has a description of each of the domains.

Domain	What measuring?	High raw score	Percentile
Parental Distress	Level of distress parent is experiencing as a function of personal factors that are directly related to parenting	36	90th
+ Parent-Child Dysfunctional Interaction	Focuses on the parent's perception that the child does not meet up to their expectations and interactions with the child are not reinforcing	27	90th
+ Difficult Child	Focuses on basic behavioural characteristics of children which make them either easy or difficult to parent	36	90th
= Total Stress	Overall level of parenting stress	90	90th

**Table 5:** Interpretation of PSI and Cut-off scores required for clinical significance

### **Use of the PSI with parents with a learning disability**

Feldman & Walton-Allen (1997) used the original items and no difficulties using the scale were reported (mean IQ=63). Feldman et al. (1997, 2002) used simpler language and clarification of the items when required for mothers with a learning disability and reported no difficulties in its use.

Some of the items were also translated into simpler English in the current study. To provide two examples, item 3 'I feel trapped by my *responsibilities* as a parent' was changed to 'I feel trapped by *all the jobs* I have to do as a parent' and item 8 'Having a child has caused more problems than I *expected* in my relationship with my *spouse*' was changed to 'Having a child has caused more problems than I *thought* in my relationship with my *boy/girl friend/husband/wife*'. Please see Appendix 8b for the original PSI as used with the control group and Appendix 8c for the adapted version for the learning disabled group.

#### **2.5.4. The Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983)**

Generalised anxiety and depression was assessed by the Hospital Anxiety and Depression Scale (HADS), a reliable brief 14-item instrument designed to screen for clinically significant anxiety (seven items) and depression (seven items). While Zigmond & Snaith (1983) suggested that scores on the two scales should be kept distinct, Crawford, Henry, Crombie & Taylor (2001) suggested that were a measure of general psychological distress required, contrary to this advice, 'it would be legitimate to combine scores on the anxiety and depression scales to obtain a score on the total scale' (p. 432). In the current study, therefore, both the anxiety and depression subscale scores and total HADS scores have been reported and classified

as 'normal' (0-7), 'mild' (8-10), 'moderate' (11-14) or 'severe' (15-21). The HADS can be repeated at intervals to assess progress. The scale is known to have high internal consistency (Cronbach's alpha coefficient = .93 for anxiety, .90 for depression) and good concurrent, face and construct validity (see Moorey, Greer, Watson, Gorman, Rowden, et al., 1991 and Zigmond & Snaith, 1983). While the HADS was originally designed for use in medical practice, many studies conducted throughout the world have confirmed it is valid when used in community, primary care and non-clinical samples (e.g. Crawford et al., 2001).

This scale was chosen in order to be able to compare results with the control group and was thought appropriate due to its ability to assess both anxiety and depression, its quick administration time and availability of an adapted version for people with a learning disability (McDowell, Dagnan & Masson, 2003). Questions have been rephrased in the adapted version, using simplified language such as item 12 *'I look forward with enjoyment to things'* has been changed to *'I get a nice feeling when I think about things I'm going to do'*. Bar graphs have also been provided to assist responses. Psychometric evaluations by McDowell et al. (2003) show acceptable reliability for the adapted version for people with a learning disability (Cronbach alpha=0.77 for anxiety and 0.54 for depression).

See Appendix 9a for the original HADS and Appendix 9b for the adapted version for the learning disabled group.

### **2.5.5. Revised Rutter Child Behaviour Scales (Elander & Rutter, 1996)**

The functioning of the children of the participants was assessed before and after the group by the Revised Rutter Child Behaviour Scales (original scales by Rutter, 1967 and Rutter et al., 1970). In addition to emotional and conduct problems, the revised scales incorporate pro-social items to assess the parents ability to make positive comments about their children. Items are rated on the basis of the child's behaviour in the past three months or during the current school year. Each item is scored '0' for 'does not apply', '1' for 'applies somewhat' and '2' for 'certainly applies'. A cut-off point of 9 or more signifies the presence of severe behavioural disturbance.

As yet there appears to be no psychometric information available on the revised scales. However, the psychometric properties of the original scales have been reported in great detail (see Elander & Rutter, 1996) and have been very widely used. The scales were chosen for the parents with a learning disability as they are fairly brief to complete yet correlate well with the much longer Child Behaviour Checklist (Achenbach & Edelbrock, 1983) and Strengths and Difficulties Questionnaire (Goodman, 1997).

Some of the items of the Rutter Scales were re-worded for the people with a learning disability to aid comprehension e.g. item 12, *'irritable, touchy, quick to fly off the handle'* to *'has a bad temper and gets angry easily'* and item 43, *'independent, confident child'* to *'can manage a lot of things on their own and doesn't need a lot of help'*. The responses were also presented as likert-type bar graphs to the parents with learning disabilities, which Lindsay (1991) notes is a particularly appropriate method for assessing the feelings of this population.

See Appendix 10a for the original Rutter Scales and Appendix 10b for the adapted version.

#### **2.5.6. The Family Support Scale (FSS), Dunst, Jenkins & Trivette (1984).**

Satisfaction with support has been found to be more important than actual size of support in buffering the effects of stress (Feldman et al., 2002). The FSS was chosen for the study as it provides both quantitative and qualitative data about support. Parents indicate the number of supports available from a list of 18, including friends, family and partner (see table 2) and then rate how helpful these supports are to them (see Appendix 11a for items included in each category and 11b for FSS).

The likert-type rating scale from 1 (not helpful) to 5 (extremely helpful) was considered particularly suitable for the parents with a learning disability as bar graphs could be provided to assist with this scale. Parents can also indicate 'not available' when applicable. The scale has high internal consistency (Cronbach's  $\alpha = .79$ ), test-retest reliability ( $r = .91$ ) and acceptable levels of content, discriminant and construct validity (see Dunst, Trivette & Cross, 1986, Dunst, Trivette & Hamby, 1994 and Frey, Fewell & Vadasy, 1989). As the majority of the data had been collected for the control groups before the groups for parents with a learning disability started, the FSS was administered to 16 of the latter control group parents. As only one of these parents attended the group, the FSS was examined as a between-subjects measure for PART A but within-subjects only (parents with a learning disability) for PART B.

### **2.5.7. Parenting Skills Assessment (used only with parents with learning disabilities)**

It was also noted that omission of a parenting scale had been an oversight with the earlier control groups and this was, therefore, employed with the parents with a learning disability as a within-subjects measure. The Parenting Scale (Arnold, O'Leary, Wolff & Acker, 1993) provided in the Triple P manual was considered too complex to adapt for the participants as it was extremely long and used a seven-point scoring key. The researcher also noted that the scale did not assess use of positive reinforcement, which literature suggests is a key deficit of parenting skills by parents with a learning disability. A scale (Appendix 12) was, therefore, devised by the researcher which included some of the items from the original Parenting Scale (Arnold et al., 1993) and specially devised items to ensure that areas of parenting difficulty highlighted in the research e.g. positive reinforcement, supervision, limit-setting and consistent discipline (Fantuzzo et al., 1986, Tymchuk et al., 1990) were assessed. Parents rated how often they used the methods (using bar graphs for 'always', 'sometimes' or 'never').

In addition to the adaptations all of the measures were read aloud and completed with the researcher in order to allow the participant the opportunity to ask for any item to be clarified or repeated.

### **2.5.8. Parent satisfaction with Triple P group**

In order to assess parent satisfaction with the intervention and to compare satisfaction across the groups, the evaluation devised by the Clinical Psychologist for the group for parents without a learning disability (Appendix 13a) was adapted for the parents

with a learning disability (Appendix 13b). Using the PSI scoring key and visual aids, participants were asked to say whether they Strongly Agreed, Agreed, Strongly Disagreed, Disagreed or were Not Sure about six statements about the group including relevance of topics, ease of understanding, presentation of information, usefulness and whether they felt better equipped to deal with their children's behaviour. Participants were then asked open-ended questions regarding what they found most and least useful about the group as well as being invited to make any additional comments. The design of this evaluation form is consistent with recommendations in the literature that to increase validity, evaluation forms should be specific (Stallard 1995) and include an opportunity for open-ended comments to obtain a less biased response (Firth & Bucknall, 2002).

## **2.6. INTERVENTION**

### **2.6.1. Positive Parenting Programme (Triple P)**

Group Triple P is for parents who require intensive training in positive parenting skills and employs an active skills training process to help parents acquire new knowledge and skills. The Triple P was considered an appropriate intervention to pilot for parents with a learning disability as areas of difficulty highlighted in the research are included in the programme e.g. positive reinforcement, supervision, limit-setting and consistent discipline. In addition, performance-based methods are used; parents are given the opportunity to learn through observation, role-play, discussion, practice and feedback.

Both groups of parents, therefore, undertook the Group Triple P program (level 4), a 10-session program (five x two hour group sessions). In addition, segments from a

video called “Every Parent’s Survival Guide” were used to demonstrate the positive parenting skills discussed in each session. The original Triple P overheads were simplified, written in larger font and supplemented with illustrations for the parents with a learning disability. See Appendix 14 for the outline of the Triple P programme, Appendix 15a for an example of an original Triple P overhead and Appendix 15b for an adapted example.

## **2.7. ANALYSIS OF DATA**

### **2.7.1. Data Analysis**

All statistical analyses were carried out using the Statistical Package for Social Sciences (SPSS) for Windows 95, version 10. When the assessments were completed the results were entered into a database with no identifying information.

Prior to statistical analysis, the data was examined for normality<sup>3</sup> and outliers<sup>4</sup>. Parametric tests were used in PART A (i.e. independent t-test) with the exception of two analyses where non-parametric tests (i.e. Mann-Whitney) were also employed due to deviation from normality. As the samples were small in PART B, the central limit theorem could not be used to justify the use of parametric tests and any test of normality would have had little power, hence the non-parametric Wilcoxon Analysis was employed. Where outliers were detected in both PART A and PART B, these were removed and the analyses were repeated.

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<sup>3</sup>Tests for normality involved examining skewness and kurtosis for each of the variables – a value for skewness or kurtosis greater than 1.96 x the respective standard error value indicates a significant departure from normality.

<sup>4</sup>Outliers were determined by examination of stem-and-leaf plots and box plots.



### **2.7.2. Statistical Power**

Previous studies investigating the effect of parenting intervention with people with learning disabilities report mostly medium to large effect sizes. As parenting interventions are considered optimal for parents with learning disabilities, a large effect size was anticipated (0.80). Cohen's (1992) criteria on statistical power states that for a large effect size at  $p < 0.05$ , around 26 treatment participants are needed to achieve a power of 0.8.

Based on discussions with Community Learning Disability Nurses, it was anticipated that over 20 referrals would be received across the whole Tayside area. The researcher was mindful that while Cohen's (1992) power criteria was likely to be satisfied for PART A of the study, parenting groups generally have a high attrition rate. However, previous studies demonstrating significant effects of parent training with people with learning disabilities have been based on very small numbers, ranging from single case studies (e.g. Sarber et al., 1983) to a group of 12 at the most (McGaw, Ball & Clark, 2002). For example, two studies which employed group intervention (Peterson et al., 1983, Tymchuk et al., 1990), found large effect sizes with a small number of mothers with learning disabilities ( $n=6$  and  $n=8$  respectively). The effect size and power with even small numbers was sufficient to detect a change, which suggests the power of PART B of the study should be adequate despite a possible high attrition rate.

## **CHAPTER THREE**

### **RESULTS**

### **3.1.Presentation of results**

The demographics of participants from PART A are explored for significant differences followed by an initial multivariate analysis of PART A data. The assessment data is then statistically analysed to examine the hypotheses of PART A. The demographics of participants in PART B and a mixed analysis of variance are then examined. The hypotheses of PART B of the study are then analysed in turn, including the results of the six-week follow-up assessments. Throughout this section 'pre' refers to PART A data collected before the group, 'post' refers to data collected immediately after the group and 'follow-up' refers to the six-week follow-up assessment.

### **3.2. PART A – Pre-group analyses - The social and emotional lives of parents with a learning disability**

#### **3.2.1. Demographic information**

The t-test showed no significant difference between the groups in terms of parental age ( $t=0.55$ ,  $df=46$ ,  $p=.58$ ), age of the child ( $t=0.06$ ,  $df=46$ ,  $p=.95$ ) and number of children per parent ( $t=1.13$ ,  $df=46$ ,  $p=.26$ ).

The two groups were, therefore, well matched in terms of mean age of parent (mean=33.8yrs,  $SD=6.55$ ) children (mean=7.6yrs,  $SD=3.27$ ) and number of children (mean=2.8,  $SD=1.46$ ) and no outliers were found in these demographic variables.

The deprivation index scores of the two groups were significantly different ( $t=2.5$ ,  $df=46$ ,  $p<.05$ ) showing that the parents with a learning disability were on average one band lower (mean = 4.9,  $SD=1.59$ ) than the parents without a learning disability

(mean = 3.9, SD=1.27). The results were unchanged with the removal of three outliers (DEPCAT score <3) in the group of parents with a learning disability ( $t=6.89$ ,  $df=41$ ,  $p<.001$ , equal variances not assumed).

### 3.2.2. Initial multivariate analysis of data

Prior to examining the hypotheses individually, the between-group dependent variables (parental stress, anxiety and depression, child behaviour and social support) were examined in a multivariate analysis<sup>5</sup>. As the Family Support Scale was completed on 16 parents in the control group, the initial multivariate analysis was based on  $n=16$  across all the measures. This showed an overall effect of group ( $f=3.5$ ,  $df=4,29$ ,  $p<.05$ ). This result was due to a specific effect of the Rutter Behaviour Scale ( $f=7.2$ ,  $df=1$ ,  $p<.05$ ) and Family Support Scale ( $f=9.3$ ,  $df=1$ ,  $p<.01$ ). When the Family Support Scale is excluded from the multivariate analysis to allow full sets of data (total  $n=48$ ) the effect of group is nearing significance ( $f=2.74$ ,  $df=3,44$ ,  $p=.58$ ). This shows a specific effect of the Rutter Behaviour Scale ( $f=6.9$ ,  $df=1$ ,  $p<.05$ ). The post-hoc power and effect sizes are detailed in table 6 for both multivariate analyses.

	Power	Effect size	Pqwer (3 variables)	Effect size (3 variables)
<b>PSI</b>	.12	.02	.18	.02
<b>HADS</b>	.05	.00	.08	.00
<b>RUTTER</b>	.74	.18	.73	.13
<b>FSS</b>	.84	.22		

*Table 6: Post hoc power and effect size based on multivariate analysis of four dependent variables.*

<sup>5</sup>This analysis served to protect the familywise alpha level

The measures will now be examined individually and in relation to the hypotheses for a more detailed exploration of results.

### **3.3. HYPOTHESES FOR PART A OF THE STUDY**

#### **3.3.1. Hypothesis A1**

**The parents with a learning disability will be experiencing high levels of parental stress and levels greater than the control group.**

None of the parents in any of the samples scored greater than 10 on the defensive responding scale, suggesting none were trying to mislead the researcher and create a favourable impression.

Significant levels of parental stress were found in 72.2% of the group of parents with a learning disability and 93.3% of the parents without a learning disability (i.e. PSI score > 90). Not consistent with the hypotheses, the parents without a learning disability had a slightly higher mean score (118.37) than parents with a learning disability (111.89). This difference was not significant ( $t = 1.06$ ,  $df=46$ ,  $p=.30$ ).

The parents without a learning disability also had higher mean scores on all the subscales of the PSI, however, no significant differences were found between the groups. Both group means placed them above Abidin's (1995) cut-off for a 'high' raw score on all subscales, suggesting significant problems in all areas (with the exception of parental distress by parents with learning disabilities). An exploration of the PSI data revealed one outlier in the difficult child subscale for the parents with learning

disabilities group, although removing this participant (number 45) from the analysis did not change the non-significant results ( $t=1.9$ ,  $df= 25$   $p=.07$ , equal variances not assumed). Table 7 shows the means, standard deviations (SD) and percentile ranks for both groups on the PSI.

	<b>Learning Disability mean (SD)</b>	<b>%tile rank</b>	<b>Non Learning Disability mean (SD)</b>	<b>%tile rank</b>	<b>T-test</b>	<b>High raw score cut-off</b>
<b>Total stress</b>	111.9 (22.16)	99+	118.37 (19.54)	99+	$t=1.06$ , $df= 46$ $p=.30$	90
<b>Parental Distress</b>	35.4 (8.38)	85-90	37.0 (9.85)	90-95	$t=0.55$ , $df= 46$ , $p=.59$	36
<b>Parent-Child Dysfunctional Interaction</b>	35.8 (6.96)	99+	36.2 (7.84)	99+	$t=0.16$ , $df= 46$ , $p=.87$	27
<b>Difficult Child</b>	40.6 (10.39)	95-99	45.1 (7.27)	95-99	$t=1.61$ , $df= 27$ , $p=.12^*$	36

\* Levene's test for equality of variances significant ( $p<0.05$ ), therefore, equal variances not assumed

*Table 7: Group mean scores, (standard deviations), percentile ranks and t-test results for the Parental Stress Index*

### 3.3.2. Hypothesis A2

**The parents with a learning disability will be experiencing high levels of anxiety and depression and of a greater severity than the control group.**

Both the mean scores of the parents with and without learning disabilities on the HADS placed them within the 'severe' category (means=18.5 and 17.5 respectively) and therefore hypothesis B2 was not supported. The one-point difference between the

groups was not significant ( $t=0.50$ ,  $df= 46$ ,  $p=.62$ ). No significant difference was found between the groups on the t-test when the anxiety and depression items were examined separately ( $t=1.26$ ,  $df=46$ ,  $p>.21$  and  $t=0.48$ ,  $df=46$ ,  $p=.63$  respectively) and both groups had very similar mean scores on these subscales also. Table 8 shows the mean and standard deviations for the two groups on the HADS which also demonstrates that both sets of parents were experiencing higher levels of anxiety than depression.

	<b>Learning disability mean (SD)</b>	<b>Non learning disability mean (SD)</b>
<b>Total HADS score</b>	18.5 (7.63)	17.5 (7.12)
<b>Depression</b>	6.78 (3.60)	7.3 (4.00)
<b>Anxiety</b>	11.8 (5.20)	10.1 (3.83)

*Table 8: Group mean scores and (standard deviations) for the HADS*

### 3.3.3. Hypothesis A3

**The children of parents with a learning disability will have a high number of behavioural difficulties and more difficulties than the control group.**

Both group means were well above the cut-off for behavioural problems ( $score>9$ ). However, hypotheses A3 was not confirmed as the parents without a learning disability had higher levels of total child behaviour problems ( $mean=26.1$ ) than the parents with a learning disability ( $mean=21.2$ ). This difference was significant ( $t=2.63$ ,  $df=46$ ,  $p<.05$ ). Removal of three outliers (participants numbers 21, 32 and

45) from the learning disability group did not affect this significant result ( $t=3.62$ ,  $df=43$ ,  $p<.01$ ).

Exploration of the subscales revealed no significant differences between the groups on conduct ( $t=1.74$ ,  $df=46$ ,  $p=.09$ ) and hyperactive items ( $z=0.36$ ,  $p=.71$ )<sup>6</sup>. An outlier was discovered in the group with learning disabilities for the hyperactive subscale (participant number 5) and removal of this did not change the non-significant result ( $t=0.30$ ,  $df=45$ ,  $p=.77$ ). The scores on the emotional problems subscale did, however, show a significant result as the parents without a learning disability had children with significantly higher levels of emotional problems ( $t=3.37$ ,  $df=46$ ,  $p<.01$ ). This result remained the same when an outlier in the group with learning disabilities (participant number 18) was removed ( $t=4.44$ ,  $df=45$ ,  $p<.001$ ). Both groups received similar mean scores for the pro-social items showing no significant differences ( $t=0.09$ ,  $df=46$ ,  $p=.93$ ) between the groups in terms of being able to make positive statements about the children. Table 9 shows the mean scores and standard deviations for the two groups on the Rutter behaviour scales.

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<sup>6</sup> Non learning disability data for hyperactive subscale deviated from normality therefore non-parametric test (Mann-Whitney) employed. Transformation of the data did not remove skewness. However, as the robustness of parametric tests has been noted even when some assumptions are violated (Clark-Carter, 1997), to retain sufficient power, parametric test also conducted. This also showed a non-significant difference between the groups ( $t=0.11$ ,  $df=46$ ,  $p=.91$ ).



	<b>Learning Disability mean (SD)</b>	<b>Non- Learning Disability mean (SD)</b>
<b>Total score</b>	<b>21.2</b> (5.00)	<b>26.1</b> (6.72)
<b>Emotional</b>	<b>2.5</b> (1.76)	<b>4.7</b> (2.41)
<b>Conduct</b>	<b>4.5</b> (2.01)	<b>5.6</b> (1.91)
<b>Hyperactive</b>	<b>4.4</b> (1.58)	<b>4.5</b> (1.76)
<b>Prosocial</b>	<b>11.6</b> (3.36)	<b>11.5</b> (4.40)

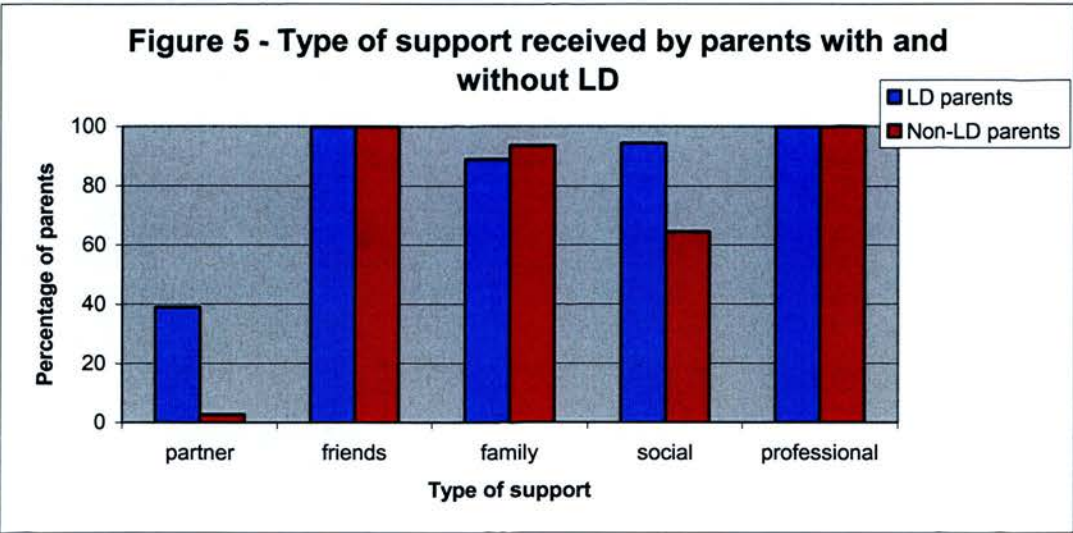
*Table 9: Group mean scores and (standard deviations) for the Rutter Behaviour Scales.*

#### 3.3.4. Hypothesis A4

**The parents with a learning disability will have lower levels of social support than the control group and be less satisfied with these supports.**

**Quantitative support (number of supports):** The mean number of supports reported by parents without a learning disability (mean=10.9, SD= 2.42) was higher than the number reported by parents with a learning disability (mean=8.7, SD= 1.67, equal variances not assumed). This t-test confirmed the hypotheses that the parents without a learning disability would have a significantly higher number of social supports, ( $t=2.98$ ,  $df=26$ ,  $p<.01$ ).

**Type of support received:** Figure 5 illustrates the percentage of parents who indicated at least one support in each of the categories.



**Figure 5:** Supports accessed by parents with and without a learning disability

As can be seen from figure 5, all of the parents in both groups indicated at least one type of professional support and informal friendship. More parents with than without a learning disability indicated support from partners and social organisations, although slightly fewer parents with a learning disability were receiving support from family.

**Qualitative support (helpfulness of supports):** Not consistent with the hypothesis, the parents with a learning disability rated all their supports (where available) with the exception of family as, on average, significantly more helpful than the parents without a learning disability. An outlier (participant number 44) in the parents without a learning disability group did not change the significant t-test result for helpfulness of partner ( $t = 4.00$ ,  $df=18$ ,  $p<.01$ ). Please see table 10 for an outline of results and statistical analysis for each support.

	<b>Learning Disability mean (SD)</b>	<b>Are supports helpful?</b>	<b>Non-Learning Disability mean (SD)</b>	<b>Are supports helpful?</b>	<b>T-test</b>
<b>Partner</b>	4.1 (1.13)	Very	2.7 (0.94)	sometimes	t=3.0, df= 20, p<.01
<b>Friends</b>	3.5 (1.27)	Generally	2.4 (0.84)	sometimes	t=2.9, df=32, p<.01
<b>Family</b>	3.7 (1.31)	Generally	3.5 (1.22)	generally	t=0.48, df=29, p=.63
<b>Social</b>	4.0 (1.12)	Very	2.6 (1.33)	sometimes	z=3.08, p<0.05*
<b>Professional</b>	4.1 (0.68)	Very	2.8 (1.23)	sometimes	t=3.68, df=23, p<.01**
<b>Overall mean</b>	3.9 (0.27)	Generally	2.8 (0.42)	sometimes	t=4.86, df=8, p<.001

\* Conducted due to deviating from normality, parametric test ( $t=3.13$ ,  $df=27$ ,  $p<.01$ ).

\*\* Levene's test for equality of variances significant ( $p<0.05$ ), therefore, equal variances not assumed

*Table 10: Group mean scores,( standard deviations) and t-test results for the FSS for perceived helpfulness of social supports.*

### 3.3.5. Hypothesis A5

**The parents with a learning disability will show low levels of praise and high levels of ineffective punitive parenting techniques.**

This assessment was used only with the parents with a learning disability. A summary is provided of the responses, organised in terms of the areas of parental management assessed and qualitative information is noted where appropriate.

**Positive Reinforcement (see Appendix 12, questions 1-3):** In response to the question of whether the parents said “well done” when their child had done something good, 14 parents stated that they ‘always’ did this and the remainder noted that they ‘sometimes’ did. Five parents said that they ‘always’ and 12 said they ‘sometimes’ gave their child rewards for good behaviour. All of these parents were able to give examples of rewards given to their children. All rewards listed were material in nature (e.g. food treats, toys, money, CD’s, videos). The remaining parent said that she disagreed with rewards and believed they were ‘blackmail’. The responses did not support the hypothesis that the parents would show low levels of praise.

**Stimulation and affection (questions 4 and 6):** While 9 of the parents stated that they could ‘always’ think of nice things to do/talk about with their child, only 3 of these 9 parents could give examples. These included going to the beach, playing games, drawing, bowling and shopping. One parent noted it would depend on the child’s age. In terms of what to talk about with their child only one parent made a suggestion (i.e. school). One parent noted spending time with children was ‘natural’ and another said they could talk about ‘anything’. None of these parents could elaborate on these comments. Of the 8 parents who said they could ‘sometimes’ think of things to do/talk about, only half were able to give examples. The remaining parent replied ‘never’ to this question. All of the parents said they could either ‘always’ (12 parents) or ‘sometimes’ (6 parents) show their children affection.

**Discipline methods (question 7):** The responses to the methods of discipline used are outlined in Table 11.

	<b>Always</b>	<b>Sometimes</b>	<b>Never</b>
<b>Smack</b>	1	6	11
<b>Shout/lose temper</b>	8	7	3
<b>Ignore/walk away</b>	2	14	2
<b>Consequences</b>	4	13	1
<b>Swear/call names</b>	1	8	9
<b>Time-out</b>	4	8	6

*Table 11: Methods of discipline used by the parents with a learning disability – number in each category*

Most of the parents who did not smack spontaneously commented that it was ‘not allowed’. The two parents who said that they ‘never’ ignored difficult behaviour stated that children should never be ignored. From the 17 parents who indicated the use of consequences, only 5 gave specific examples (e.g. toys, computer, television, money). From the 12 parents that used time-out, the majority gave an example of sending them to their bedrooms and two spontaneously commented it should be for around 5 minutes. Most of the parents who did not use time-out said that the child just came out of the room or destroyed it. A common statement with all the methods was that they had ‘tried it but it didn’t work’. Only one parent gave an additional method, which was to use distraction or to hug her child when upset. Some of the parents reported that they had been advised to use certain methods (e.g. ignoring) by professionals involved. The results suggest a varied pattern of discipline methods and therefore hypothesis A5 was only confirmed for some of the parents.

**Consistency/frequency (question 8):** Twelve of the parents said that they used discipline methods immediately after their child had misbehaved and 6 admitted to only doing this ‘sometimes’. Ten said they intervened every time the behaviour occurred and 8 only intervened sometimes.

**Limit-setting/effectiveness (questions 5, 9, 10, 11):** Eight parents said that they ‘always’ and an equal amount, ‘sometimes’ used house-rules. Only half of these mothers, however, could give examples and the majority only mentioned trying to have a set bed-time. Other examples noted were taking shoes off at the door, putting dirty dishes in the sink, tidying bedrooms and keeping out of the kitchen. One parent said that her children were to change into their nightwear immediately after school (i.e. 4pm). The majority of the sample (15 parents) admitted that when they said ‘no’ to their children they often let them do it anyway, which one parent mentioned was to ‘keep the peace’. The majority (16 parents) also admitted that they threatened to punish their children and then did not carry it out.

**Supervision (question 12):** All the parents except one said that they ‘always’ knew where their children were when not with them. The parent who replied ‘never’ commented that her children were teenagers and that they tended to go out without telling her about their plans.

### **3.3.6. Summary of Results - PART A**

The mean group scores of parents, both with and without a learning disability, were above the clinical cut-offs on the PSI, HADS and Rutter Behaviour Scales. Both groups also fell within the ‘severe’ range on the HADS. There were no significant differences between the groups on the total PSI stress score or subscales. Likewise, no significant differences were found in general anxiety and depression, as measured by the HADS. On the Rutter Child Behaviour Scales, the parents without a learning disability were found to have significantly higher levels of total child behavioural problems and emotional difficulties. In terms of social support, while the parents with

a learning disability were found to have significantly less quantitative levels of support, on average, the supports they did have were shown to be significantly more helpful (with the exception of family) than the parents without a learning disability. The parenting scale looking at child management indicated that the majority of parents were aware of praise, management techniques such as time-out and some positive ways to spend time together. However, many of these parents could not supplement their responses with examples.

### **3.4. PART B – The impact of a positive parenting programme on psychological well-being**

As outlined earlier, nine of the 18 parents with learning disabilities attended the Triple P pilot groups and therefore participated in PART B of the study. Of the 30 parents without learning disabilities assessed in PART A, 8 of these attended a Triple P group for parents without a learning disability. Data for PART B is therefore based on 9 parents with a learning disability and 8 parents without a learning disability. Six week follow-up data was not available for parents without a learning disability and six sets of follow-up data were available for parents with a learning disability.

#### **3.4.1. Demographic information**

The Mann-Whitney test confirmed there was no significant difference between the groups in PART B in terms of parental age ( $z=0.00$ ,  $p=1.00$ ) age of the child ( $z=1.16$ ,  $p=.25$ ) and number of children per parent ( $z=1.80$ ,  $p=.07$ ). The demographic details are presented in table 4. The participants in PART B also did not differ significantly in terms of SES status as per deprivation index scores ( $z=1.00$ ,  $p=.31$ ).



### **3.4.2. Initial Mixed Analysis of Variance**

This analysis was conducted on the between-group variable (LEARNING DISABILITY v NON LEARNING DISABILITY) and outcome measures administered with both groups (i.e. PSI, HADS and RUTTER). The factor group did not have a main effect ( $f=1.38$ ,  $df=1,15$ ,  $p=.26$ , effect size=0.08, power=0.2), neither did the interaction between group and measures ( $f=0.80$ ,  $df=11.37$ ,  $p=0.48^7$ , effect size=0.05, power=0.19). Pre-post within-subjects t-tests have therefore been employed in relation to the hypotheses of PART B to examine if intervention led to improvement on the measures by each of the groups.

## **3.5. HYPOTHESES FOR PART B OF THE STUDY**

### **3.5.1. Hypothesis B1**

**The positive parenting group for parents with a learning disability will reduce parental stress.**

Following treatment there was a significant decrease in mean total parental stress scores (pre and post mean 113 and 102 respectively) for the parents with a learning disability ( $z=2.55$ ,  $p=.01$ ). The post-treatment mean did, however, continue to place them above the 90<sup>th</sup> percentile for parental stress. Although the parents without a learning disability also had decreased parental stress scores (pre and post mean 113 and 107 respectively) the result of the Wilcoxon analysis was not significant ( $z=0.42$ ,  $p=.67$ ) and also continued to place them above Abidin's cut-off for significant parental stress.

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<sup>7</sup>Mauchly's test of sphericity significant ( $p<0.01$ ) therefore more conservative Greenhouse-Geisser test employed.



The parents with a learning disability also had reduced mean scores for the subscales (see table 12). The decrease in the parental distress and difficult child subscales were not significant ( $z=1.69$ ,  $p=.09$  and  $z=1.76$ ,  $p=.08$  respectively). The decrease in scores on the parent-child dysfunctional interaction subscales was significant ( $z=2.49$ ,  $p=.01$ ). Although the parents without learning disabilities also had reduced scores on the parental distress, parent-child dysfunctional interaction and difficult child subscales, none of these were significant ( $z=0.51$ ,  $p=.61$ ,  $z=.028$ ,  $p=.78$  and  $z=1.16$ ,  $p=.25$  respectively). Removal of an outlier on the parent-child dysfunctional interaction subscale did not alter the results ( $z=0.68$ ,  $p=.50$ ).

	Learning Disability mean (SD)		Non learning Disability mean (SD)	
	PRE	POST	PRE	POST
<b>Total Stress</b>	<b>113.4</b> (27.10)	<b>102.0</b> (27.5)	<b>112.6</b> (9.78)	<b>107.0</b> (18.04)
<b>Parental Distress</b>	<b>35.9</b> (9.92)	<b>32.1</b> (10.50)	<b>33.4</b> (8.20)	<b>31.9</b> (4.85)
<b>Parent-Child Dysfunctional Interaction</b>	<b>36.0</b> (6.95)	<b>31.2</b> (8.73)	<b>33.7</b> (8.28)	<b>32.9</b> (8.53)
<b>Difficult Child</b>	<b>41.5</b> (12.30)	<b>38.7</b> (10.80)	<b>45.5</b> (6.72)	<b>42.2</b> (9.97)

*Table 12: Pre and post group mean scores and (standard deviations) for both groups on the PSI*

At six-week follow-up (six parents with learning disabilities), although the total PSI scores had further decreased (see table 13) the Wilcoxon Analysis was not significant ( $z=1.36$ ,  $p=.17$ ). The mean group score, however, (89.2) now fell below the 90<sup>th</sup>

percentile for parental stress, placing the participants below the cut-off for significant parental stress. As the follow-up score was significantly less than the pre PSI score ( $z=2.20$ ,  $p<.05$ ), the results of intervention on parental stress were maintained. Unlike the original sample, the Wilcoxon Analysis on these six sets of scores resulted in a significant pre-post decrease for parental distress ( $z=1.05$ ,  $p<.05$ ), difficult child ( $z=2.03$ ,  $p<.05$ ) and was nearing significance for parent-child dysfunctional interaction ( $z=1.90$ ,  $p=.058$ ). At follow-up assessment the mean scores for parental distress and difficult child had significantly decreased from the post-group assessment ( $z=2.21$ ,  $p<.05$  and  $z=2.02$ ,  $p<.05$  respectively), although the decrease for parent-child dysfunctional interaction ( $z=0.42$ ,  $p=0.67$ ) was not significant.

	<b>Pre mean (SD)</b>	<b>Post mean (SD)</b>	<b>Follow-up mean (SD)</b>
<b>Total stress</b>	117.0 (26.82)	104.5 (26.92)	89.2 (26.91)
<b>Parental Distress</b>	37.2 (11.20)	33.7 (10.69)	27.2 (9.58)
<b>Parent-Child Dysfunctional Interaction</b>	37.2 (5.64)	32.2 (8.06)	31.2 (7.14)
<b>Difficult Child</b>	42.7 (12.61)	38.7 (11.16)	30.8 (12.07)

*Table 13: Pre, post and six-week follow-up group mean scores and (standard deviations) for six parents with a learning disability on the PSI.*

### 3.5.2. Hypothesis B2

**The positive parenting group for parents with a learning disability will improve levels of anxiety and depression.**

This hypothesis was not supported as following treatment, the small mean decrease on the HADS by the parents with a learning disability (pre mean=18.5, post mean=17.7) was not significant ( $z=0.36$ ,  $p=.72$ ). The group continued to show 'severe' levels of anxiety and depression after treatment. Table 14 shows there was very little change in the anxiety and depression subscale mean scores and neither of these were significant ( $z=0.36$ ,  $p=.72$  and  $z=0.43$ ,  $p=.67$  respectively). Of interest, unlike the larger sample in PART A of the study, this sample would confirm hypothesis A1 by showing higher levels of anxiety and depression than the control group. The same pre-post non-significant results were found for the six participants who attended the six-week follow-up assessment where non-significant results continued to be found for total score ( $z=0.74$ ,  $p=.46$ ), anxiety ( $z=1.07$ ,  $p=.28$ ) and depression ( $z=1.40$ ,  $p=0.69$ ).

Similarly, there was no significant difference on the total HADS score for parents without learning disabilities ( $z=0.70$ ,  $p=.48$ ), including the depression ( $z=0.51$ ,  $p=.61$ ) and anxiety ( $z=1.19$ ,  $p=.23$ ) subscales. Table 14 shows that the mean scores for these parents *increased* after treatment from the 'moderate' to 'severe' categorisation of mental health problems on the HADS and there was also a slight increase in the anxiety subscale.

	Learning Disability mean (SD)		Non learning Disability mean (SD)	
	PRE	POST	PRE	POST
<b>Total HADS</b>	18.5 (9.42)	17.7 (6.42)	13.9 (5.62)	15.5 (6.21)
<b>Depression</b>	6.9 (4.04)	6.5 (3.50)	4.7 (3.15)	4.9 (3.87)
<b>Anxiety</b>	11.7 (5.96)	11.1 (3.98)	9.1 (3.14)	10.6 (2.87)

*Table 14: Pre and post group mean scores and (standard deviations) for both groups on the HADS.*

### 3.5.3. Hypothesis B3

The positive parenting group for parents with a learning disability will result in a decrease in child behaviour scores.

There was very little change in group mean (pre=19.9, post=19.0) for total child behaviour problems following treatment for the parents with a learning disability and this was, therefore, not significant ( $z=0.77$ ,  $p=.44$ ). There was also no significant change in the emotional, conduct and hyperactive subscale scores ( $z=0.14$ ,  $p=.89$ ,  $z=0.65$ ,  $p=.52$  and  $z=1.02$ ,  $p=.30$  respectively). Hypothesis B3 was therefore not confirmed. Despite an increase in mean scores on the prosocial items (pre =12.3, post=14.8) this difference was not significant ( $z=1.78$ ,  $p=.07$ ). The same pre-post group results were found with the six participants who attended the six-week follow-up and there remained a non-significant difference for total score ( $z=0.27$ ,  $p=.79$ ), emotional difficulties ( $z=0.55$ ,  $p=.58$ ), conduct difficulties ( $z=0.42$ ,  $p=.67$ ) and hyperactive behaviour ( $z=0.11$ ,  $p=.91$ ). The increase between pre-prosocial score

(mean=12.8, SD=4.02) and follow-up prosocial score (mean=15.8, SD=2.14) was, however, nearing significance ( $z=1.90$ ,  $p=0.058$ ), suggesting an increase in the parents ability to view their child positively six weeks after completion of the group.

The mean total score was also very similar pre (24.2) and post (24.7) for the parents without learning disabilities and was not significant ( $z=0.51$ ,  $p=.61$ ). Likewise, the emotional ( $z=0.00$ ,  $p=1.00$ ), conduct ( $z=0.18$ ,  $p=.85$ ) and hyperactive ( $z=0.27$ ,  $p=.78$ ) subscale scores were similar pre and post-treatment and were not significant.

Following treatment, all participants in both groups continued to score  $> 9$  on total child behaviour difficulties (and  $>9$  at six-week follow-up for the parents with learning disabilities) suggesting significant levels of behavioural difficulties persisted after treatment. The means and standard deviations for the pre-post analysis are presented in table 15.

	Learning Disability mean (SD)		Non learning Disability mean (SD)	
	PRE	POST	PRE	POST
<b>Total difficulties</b>	<b>19.9</b> (5.01)	<b>19.0</b> (4.27)	<b>24.2</b> (7.65)	<b>24.7</b> (8.22)
<b>Emotional</b>	<b>2.9</b> (1.27)	<b>3.0</b> (2.00)	<b>3.9</b> (2.70)	<b>3.9</b> (3.27)
<b>Conduct</b>	<b>4.4</b> (1.81)	<b>4.0</b> (1.22)	<b>5.2</b> (2.12)	<b>5.4</b> (2.39)
<b>Hyperactive</b>	<b>4.2</b> (1.99)	<b>3.5</b> (1.13)	<b>4.9</b> (1.25)	<b>4.7</b> (1.03)
<b>Prosocial mean</b>	<b>12.3</b> (3.50)	<b>14.8</b> (3.46)	<b>12.1</b> (3.56)	<b>12.0</b> (2.83)

*Table 15: Pre and post group mean scores and (standard deviations) for both groups on the Rutter Behaviour Scales.*

#### 3.5.4. Hypothesis B4

The positive parenting group for parents with a learning disability will increase social support scores and perceived helpfulness of supports.

**Quantitative support:** After participation in the Triple P the number of total supports increased from a mean of 8.9 (SD=1.76) to a mean of 10.0 (SD=1.80) for the parents with a learning disability. This increase was significant ( $z=2.4$ ,  $p=.01$ ). This was generally due to the parenting group now being included in the list of supports. The pre-post results were the same for the six participants attending the follow-up and the total number of supports (mean=9.8, SD=1.83) continued to be significantly higher than the pre-group number ( $z=2.12$ ,  $p<.05$ ). There was no significant difference

between post and follow-up number of supports ( $z=1.00$ ,  $p=.32$ ) suggesting the increase was maintained but did not increase further.

**Qualitative support:** There was no significant difference in any of the supports in terms of mean perceived helpfulness, despite an increase in rating from ‘generally’ to ‘very’ helpful for friends ( $z=1.36$ ,  $p=.17$ ) and social supports ( $z=1.61$ ,  $p=.11$ ). Pre-post rating scores for family and professionals were very similar and non-significant ( $z=0.37$ ,  $p=.71$  and  $z=0.42$ ,  $p=.67$  respectively). The decrease in perceived helpfulness score for partners was not significant ( $z=1.63$ ,  $p=.10$ ). Supports were, therefore, rated on average as ‘generally’ helpful both before and after treatment. The results were the same for the six participants attending follow-up appointments and there are no significant results to report at six-week follow-up. Supports continued to be rated, on average, as ‘generally’ helpful. Please see table 16 for an outline of the pre-post group results.

	PRE mean (SD)	Are supports helpful?	POST mean (SD)	Are supports helpful?
<b>Partner</b>	<b>4.1</b> (1.44)	very	<b>3.4</b> (2.29)	generally
<b>Friends</b>	<b>3.2</b> (1.62)	generally	<b>4.0</b> (1.00)	very
<b>Family</b>	<b>3.7</b> (1.75)	generally	<b>3.4</b> (2.19)	generally
<b>Social</b>	<b>3.2</b> (1.78)	generally	<b>4.2</b> (1.02)	very
<b>Professional</b>	<b>4.2</b> (0.69)	very	<b>4.1</b> (0.88)	very
<b>Overall mean</b>	<b>3.7</b> (0.48)	generally	<b>3.8</b> (0.39)	generally

*Table 16: Pre and post group mean scores and (standard deviations) for helpfulness ratings of supports on Family Support Scale.*

### 3.5.5. Hypothesis B5

**The positive parenting group for parents with a learning disability will increase levels of praise and effective child behaviour management strategies.**

Responses at pre, post and six-week follow-up on the items on positive reinforcement and interaction with children have been detailed in table 17. The results include a pre-post increase from 6 to 10 parents who could ‘always’ think of different rewards to give their children and show affection (topics frequently discussed during Triple P). Although a smaller sample after treatment indicated ‘always’ being able to think of nice things to do with their children, the parent indicating ‘never’ responded ‘sometimes’ at post-treatment. The parents were able to list different rewards (e.g. take swimming, buy computer games, give a hug) and things to talk about with the children (e.g. nursery, spiderman, boyfriends) with ease after treatment and responses



were richer in variety. The parent who stated rewards were ‘blackmail’ in PART A did not make this statement post-treatment and said she ‘sometimes’ used them. At six-week follow up the majority of the sample fell into the ‘always’ or ‘sometimes’ category for each of the items. The results therefore confirmed hypothesis B5.

	PRE N=9			POST N=9			F.U. N=6		
	A	S	N	A	S	N	A	S	N
When my child has done something good I say “well done”	8	1	0	6	2	1	3	3	0
I reward my child for good behaviour	1	7	1	1	7	1	2	3	1
I can think of different rewards	3	3	3	5	3	1	3	2	1
I can think of nice things to do/talk about with them	5	3	1	4	5	0	3	3	0
I can show my child affection	5	3	1	6	2	1	4	1	1

*Table 17: Positive parenting items: Pre, Post and 6-week follow-up (F.U.) responses in terms of number of parents indicating always (A), sometimes (S) or never (N)*

The pre, post and six-week follow-up treatment responses to the items on discipline methods are detailed in table 18. Comparing pre and post-treatment results, there was an increase in the use of the time-out strategy and ignoring difficult behaviour. Shouting reduced from the majority (4 parents) indicating ‘always’, pre-treatment, to ‘sometimes’, post-treatment. An additional parent at post-treatment also indicated she ‘never’ swore or called her child names. The use of smacking and consequences generally remained the same (where the majority indicated ‘sometimes’ using these methods) pre and post-treatment. At six-week follow-up the majority were not

smacking or using inappropriate verbal behaviour, ‘always’ using time-out and consequences and ‘sometimes’ ignoring difficult behaviour. While the majority did continued to ‘sometimes’ shout and lose their temper, Hypothesis B5 was confirmed as there was an increase in effective management strategies.

	PRE N=9			POST N=9			F.U. N=6		
	A	S	N	A	S	N	A	S	N
Smack	0	3	6	0	5	4	0	2	4
Shout/lose temper	4	3	2	3	4	2	1	4	0
Ignore/walk away	1	6	2	2	6	1	3	3	0
Consequences	3	6	0	3	6	0	3	2	1
Swear/call names	1	3	5	0	3	6	0	1	5
Time-out	1	5	3	2	6	1	3	2	1

*Table 18: Pre, post and 6-week follow-up responses in terms of number of parents indicating use of discipline methods – Always (A), Sometimes (S), Never (N)*

**Consistency/frequency:** After treatment there was an increase from 5 to 14 parents who intervened immediately for misbehaviour and increase from 5 to 16 parents who took action every time the behaviour occurred. At six-week follow-up all the parents said that they intervened right away and all but one disciplined the child every time they misbehaved.

**Limit-setting/effectiveness:** Following treatment there was an increase from 2 to 4 parents indicating the use of house-rules and all four parents supported this response

with examples. At six-week follow-up all parents indicated the use of house-rules. Although there was no change in that the majority 'sometimes' gave in to their children's demands, the number indicating they 'never' did this increased from 0 to 4. At follow-up only one parent 'never' gave into her child's demands and the remainder admitted that they often did this, or threatened punishments that were not carried out.

**Supervision:** At pre, post and six-week follow-up, the majority of parents 'always' knew where their children were when they were not with them and as in PART A, the only mother not indicating this noted she had difficulties in knowing where her teenage daughters were.

#### **3.5.6. Hypothesis B6**

**Parents with learning disabilities will report high levels of satisfaction with the group,**

Tables 19 and 20 show that the majority of the parents in both groups strongly agreed with the six statements about the group, indicating very high levels of satisfaction. None of the parents without a learning disability disagreed with any of the statements. The parent with a learning disability who strongly disagreed that it 'was easy to join in' and 'the information was understandable' spoke of feeling a lot less able than the rest of the group. Interestingly, she had the highest intellectual functioning (as measured by IQ) from the PART B sample (i.e. IQ=73). The mean score on the FSS for 'parenting groups' was 4 (very helpful) after treatment.

	<b>Strongly Agree</b>	<b>Agree</b>	<b>Not Sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>
<b>I could understand the information</b>	5	3	0	0	1
<b>The topics were important</b>	8	1	0	0	0
<b>I found it easy to join in the group</b>	7	1	0	0	1
<b>I found the group useful</b>	5	3	1	0	0
<b>I liked the way the information was given</b>	5	4	0	0	0
<b>I feel better able to manage my child's behaviour</b>	4	2	1	0	2

*Table 19: Satisfaction with Triple P programme (adapted questionnaire) – Number of parents with learning disabilities indicating each response*

	<b>Strongly Agree</b>	<b>Agree</b>	<b>Not Sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>
<b>The information was understandable</b>	7	1	0	0	0
<b>The topics were relevant</b>	6	2	0	0	0
<b>Group participation was easy</b>	2	2	0	0	0
<b>I found the course useful</b>	5	3	0	0	0
<b>The way in which information was presented was good</b>	6	2	0	0	0
<b>I feel better equipped to deal with my child's behaviour</b>	6	2	0	0	0

*Table 20: Satisfaction with Triple P programme- number of parents without learning disabilities indicating each response*

The qualitative responses given to the satisfaction questionnaire by both groups are detailed in table 21 and have been listed in order from most to least common comment.

	What did you like about the group?	What did you not like about the group?
<b>Learning disability group</b>	<ul style="list-style-type: none"> <li>• Meeting other parents</li> <li>• Small size of group (wouldn't have coped with larger group)</li> <li>• Getting lots of interesting information</li> <li>• Liked learning how to praise and cope with difficult behaviour</li> <li>• Parenting video</li> <li>• Friendly</li> <li>• Things taught really worked</li> </ul>	<ul style="list-style-type: none"> <li>• Nothing</li> <li>• Don't agree with all the points on the video</li> <li>• Wish group ran for longer</li> <li>• Uncomfortable speaking</li> <li>• Felt was only one speaking</li> <li>• Based on younger children</li> </ul>
<b>Non learning disability group</b>	<ul style="list-style-type: none"> <li>• How to deal with misbehaviour</li> <li>• Parenting video</li> <li>• Hand-outs (having it all explained)</li> <li>• Learning about time-out and giving rewards</li> <li>• New ideas from other parents</li> <li>• Very approachable staff</li> </ul>	<ul style="list-style-type: none"> <li>• Nothing</li> <li>• Lack of childcare facilities</li> <li>• Children should also have been involved</li> <li>• Stigma of location</li> <li>• Timing; evenings better</li> <li>• Strategies don't work with older children</li> </ul>

*Table 21: Qualitative responses to Triple P satisfaction questionnaire*

### 3.5.7. Summary of results – PART B

Following intervention there was a significant decrease in overall levels of parental stress by parents with a learning disability and this decrease was maintained at six-week follow-up. Although both groups remained above the cut-off for significant levels of parental stress at post-treatment, the parents with learning disabilities fell below the cut-off six weeks after treatment. Based on nine sets of scores non-significant results were found for all domains of the Parental Stress Index for the parents without a learning disability, although significant decreases were found when

the six sets of follow-up assessment scores were analysed. Further significant decreases in these subscales were found at six-week follow-up. The small decrease in general anxiety and depression after treatment was not significant for the parents with a learning disability and the control group showed a non-significant increase on the Hospital Anxiety and Depression Scale. No significant differences were found six weeks after treatment. Child behaviour problems for both groups remained above the cut-off after treatment and no pre-post or follow-up significant differences were found in any of the groups for any of the scales. The six-week follow-up did, however, point to an increase in ability to view the child positively. Participation in the group resulted in a significant increase of social supports for the parents with a learning disability and although some supports were rated as more helpful (i.e. friends and social organisations) after treatment, this difference was not significant. No significant differences were found at the six-week follow-up although the increase in the total number of social supports was maintained. Intervention resulted in an increase in positive reinforcement, positive parent-child interactions, consistency and appropriate discipline methods by parents with a learning disability. The groups were rated very highly in terms of consumer satisfaction by both groups of parents.

## **CHAPTER 4**

### **DISCUSSION**

#### **4.1.SUMMARY OF RESEARCH**

The recent research to emerge on parents with a learning disability has tended to limit its focus to parenting skills. Despite this group being proposed as one of the most at risk groups for mental health problems and parenting difficulties, very few studies exist which examine the psychological well-being of these parents. This pilot study, therefore, in addition to parenting skills, examined both parental stress and generalised anxiety and depression and included an investigation of other neglected research areas for this population i.e. child functioning and social support. A pilot examination of the effect of a Positive Parenting Programme on these variables was then conducted.

#### **4.2.DISCUSSION- PART A RESULTS**

**Hypothesis A1: The parents with a learning disability will be experiencing high levels of parental stress and levels greater than the control group and Hypothesis A2: The parents with a learning disability will be experiencing high levels of anxiety and depression and of a greater severity than the control group.**

There was no significant difference between the groups on the PSI and HADS and Hypotheses A1 and A2 were not confirmed. Contrary to expectation the parents with a learning disability were not experiencing significantly higher levels of parental stress and anxiety/depression than the parents without a learning disability. Both groups of mothers were found to be experiencing comparably high levels of parental stress and anxiety/depression. Levels of generalised anxiety (as measured by the HADS) in both groups were particularly problematic. This has implications for the



equality of services in Tayside, as parenting groups historically run by clinical psychology, are targeted at the general parenting population with no specialist provision or identification of parents with learning disabilities. Llewellyn (1994) found that only 20% of 28 family support services surveyed in the Australian study catered for parents with a learning disability. It would be interesting to conduct a study to examine if professionals working with parents with a learning disability are aware of the high levels of anxiety and depression these parents experience and whether these problems had been previously identified. Research has indicated a wide range of unmet medical (Kerr, McCulloch, Oliver, McLean & Coleman et al., 2003) and mental health needs (Martin, Roy & Wells, 1997) in people with a learning disability. It is perhaps less likely, therefore, that a parent with a learning disability will seek help from the GP with regard to anxiety and depression. This may be partly due to the particular fear of these parents of having their children removed (McGaw, 1996). Routine screening, for example, utilising the adapted HADS as used in this study, may be invaluable for overcoming under-identification of mental health needs with this population.

**Hypothesis A3: The children of parents with a learning disability will have a high number of behavioural difficulties and more difficulties than the control group.**

Although both groups scored well above the cut-off for behavioural problems, hypotheses A3 was not confirmed as the parents without a learning disability had children with significantly higher levels of emotional difficulties and overall child behavioural problems than the parents with a learning disability. This may be due to

the parenting group for people with a learning disability having been conducted as part of a research project and, therefore, some professionals may have referred parents for preventative or social purposes rather than current child difficulties. Some of the referrers stated that, in addition to the parenting difficulties the client was experiencing, they had made a particular referral because the parent was very socially isolated and felt she might benefit from meeting peers. The control group, however, consisted of a sample of routine clinical referrals whom were likely to have been referred to Child & Adolescent Clinical psychology due to child behaviour problems reaching crises levels. Furthermore, they had been on the waiting list for several months and therefore, problems were likely to have escalated even further. It is somewhat encouraging that those who referred parents with a learning disability in this study may have been doing so as a preventative measure, as services for parents with a learning disability are often only provided after a crisis event (Tymchuk, 1990b).

**Hypothesis A4: The parents with a learning disability will have lower levels of social support than the control group and be less satisfied with these supports.**

The hypothesis that parents with a learning disability would report fewer social supports was confirmed; the mean number of supports reported by parents with a learning disability was significantly less than the number reported by parents without a learning disability. Although some research (e.g. Llewellyn et al., 1999) has highlighted the difficulties parents with a learning disability have in accessing supports, this appears to be the first study to systemically compare levels of support with a control group of parents without a learning disability. Although accessing less

supports, the parents with a learning disability rated these supports as more helpful than the parents without a learning disability. Anecdotal comments suggested that the parents with a learning disability were less critical and more appreciative of their supports compared to the non learning disabled group who had become dismayed with some of their supports, particularly professional support and made complaints about services. This may reflect a difference in ability to be assertive or differing expectations of supports.

All the parents from both groups indicated that they accessed at least one professional type of support and one informal support (i.e. friendships). This is encouraging as McGaw et al. (2002) noted mothers with learning disabilities tend to become overly dependent on either professional or informal support and access to both is considered optimal (Llewellyn et al., 1999). The mean number of supports of the parents with learning disabilities in this study (mean=8.7) was also higher than the mean (i.e.6) found in previous studies (i.e. Llewellyn et al., 1999, Stenfert-Kroese et al., 2002).

**Hypothesis A5: The parents with a learning disability will show low levels of praise and high levels of ineffective punitive parenting techniques.**

The variety of parenting strategies indicated on the parenting skills assessment makes clear conclusions about hypotheses A5 difficult. The variation in techniques reported supports the contention that parents with learning disabilities do not form a pathological group and that there are big variations among them in their parenting abilities (Booth & Booth, 1993a). Despite praise being found to be the single most lacking behaviour of parents with learning disabilities (Feldman et al., 1986, Peterson

et al., 1982, Tymchuk & Andron., 1992), 77.8% of the parents in this sample said that they provided this to their children. In addition, their parenting style was not found to be unstimulating and limited in variety (Mira, 1982, 1984, Tymchuk et al., 1987, Tymchuk & Andron, 1988) as 50% could 'always' think of ways to spend positive time with their children. Previous research suggests that parents with a learning disability predominantly use physical punishment (Tymchuk et al., 1987, Tymchuk & Andron, 1988) whereas the parents in the present study indicated that they used a variety of disciplinary methods. The present study piloted a formal measure of parenting styles. This does, however, have the possible disadvantage that the respondents may have given 'socially appropriate' responses, which masked their true parenting strategies. This measure was also used as a within-subjects measure and did not have norms for parents without a learning disability. It was not, therefore, possible to determine if the general parenting population would have responded any differently or if the same number (i.e. one-third) would be shown to use aversive parenting techniques. The parents with learning disabilities did indicate using positive parenting strategies and the difficulty in providing examples of these may reflect limited verbal skills rather than lack of knowledge per se.

#### **4.2.1. PART A - General reflections**

It was an unexpected finding that the parents with learning disabilities were not experiencing higher levels of parental stress and mental-health problems than the control group and the control group were experiencing a *higher* level of child behavioural problems. These results were inconsistent with previous research findings (e.g. Tymchuk, 1993) which report higher levels of parental and child difficulties in parents with rather than without a learning disability. The results were also unexpected

as the parents with a learning disability were of a significantly lower socio-economic status and had fewer social supports, both of which have been proposed as having a debilitating effect on parenting (Altemeir et al., 1982). The comparison group were, however, a clinical population who had been referred to Child & Adolescent Clinical Psychology. Some degree of mental health and parenting difficulties would, therefore, be expected. Having interviewed the parents with a learning disability individually, the researcher did occasionally question the extent to which the responses reflected actual parenting practice. As previously mentioned, McGaw (1996) suggests that many parents with learning disabilities are reluctant to draw attention to their inability to cope for fear of their child being removed. Despite it being stressed to the parents that the measures were being completed for research purposes, some parents with learning disabilities did appear to try to create a favourable impression. On the Rutter Behaviour Scale one parent stated that her child had not stolen anything over the last year, then later during the interview admitted that this was not true. Some other parents who responded that they 'never' smacked their children during formal assessment were unaware that this was inconsistent with later examples they provided during an informal chat at the end of the interview. This occurred despite the author being non-judgemental and stressing both prior to and during the interview that all parents find parenting difficult at times. Only one measure formally assessed whether parents were likely to be giving socially acceptable answers (i.e. PSI). The scores on the PSI, however, indicated that this was not occurring on this measure.

The groups were matched in terms of parent age, age of child and number of children. The non-significant difference in number of children (both group means = 2) is evidence against the myth (as discussed in section 1.2.5) that parents with a learning

disability produce more children than the norm. Tymchuk & Andron (1992) found their control group had *more* children (mean 2.5) than the learning disabled group (mean 1.5).

#### **4.3.DISCUSSION - PART B RESULTS**

**Hypothesis B1: The positive parenting group for parents with a learning disability will reduce parental stress.**

Feldman et al. (1997) found that parents with learning disabilities were experiencing significant levels of parents stress. The current study both replicated and expanded these findings by demonstrating that group parent training results in significant decreases in parental stress for parents with a learning disability, therefore, supporting hypothesis B1. Furthermore, six weeks after treatment, the total parental stress scores, while not significantly decreased, had fallen below the cut-off for clinical significant levels of parental stress. It is also very promising that significant changes were noted in the parent-child dysfunctional interaction domain as an aim of Triple P is to promote more realistic expectations of the child and to reinforce positive parent-child interactions.

The parenting group for parents without a learning disability did not result in a significant decrease in mean parental stress score. The group for parents with learning disabilities may have been more effective due to the common shared theme of having a learning disability. Edgerton (1976) suggests this provides mothers with a learning disability with a 'cloak of competence' in which they can raise topics they perhaps

would have been embarrassed to in a general parenting group. Groups for parents without a learning disability may be improved by organising the group in terms of a common shared theme (e.g. groups for parents of ADHD children/school-age children/children with learning disabilities). While some service providers believe that ordinary-life principles should be followed (see Edmonds, 2000) and stigmatisation avoided by including parents with learning disabilities in generic family support services, this would not provide a 'cloak of competence' which in this study, perhaps, contributed to the decreased parental stress levels for the parents with a learning disability.

It is also noteworthy that the parents with learning disabilities, on average, attended 4.1 of the 5 group sessions, whereas the parents without learning disabilities only attended 2.5 of the sessions. This may also explain why a decrease in parental stress was found for the parents with learning disabilities only.

**Hypothesis B2: The positive parenting group for parents with a learning disability will improve levels of anxiety and depression.**

Hypothesis B2 was not confirmed as the intervention did not have a significant effect on levels of anxiety and depression in parents with or without a learning disability. Many parents, whilst completing this follow-up assessment, did however, give reasons for their choice of response and hence provided some insight into this finding. Comments from the parents with a learning disability in terms of current stressful life events included feeling anxious over moving house, difficulties with partners, as well as children being taken into part-time care. The constant socio-economic stressors

faced by these parents are unlikely to be reduced by simply attending a parenting group, hence the decrease in parental stress but not anxiety and depression. Feldman (1992) notes that due to the multiple difficulties faced by these parents (often affecting their parenting style) several concurrent interventions may be necessary (e.g. individual/marital counselling, social skills training, advocacy). Likewise, Llewellyn (1994) suggests that these socio-economic burdens may leave a parent with little time, energy or attention to learn new parenting skills. Edmonds (2000) also highlights that in addition to parenting intervention, services need to acknowledge the importance of initially addressing practical problems such as with housing or finance.

It is a problematic finding for the Triple P that the HADS scores for parents without a learning disability increased after treatment. These parents did, however, note that the follow-up assessments took place during the school holidays and that they were reporting an increased level of stress due to this. As the follow-up assessments with the parents with a learning disability were not completed during school-holidays this may in part explain the significant results on the PSI found for this group only. It would be interesting to look at the effect of school holidays on PSI and HADS scores in a future study.

**Hypothesis B3: The positive parenting group for parents with a learning disability will result in a decrease in child behaviour scores.**

Hypothesis B3 was not confirmed as the Rutter Behaviour Scales remained above cut-off for clinical significance after treatment for both the groups. While the prosocial domain of the Rutter behaviour scales did not change significantly after treatment, a



small increase was found for the parents with a learning disability suggesting an increase in the ability to identify positive attributes in the child, an area on which the Triple P focuses. The six-week follow-up also suggested a further increase in the ability to view the child positively.

While child behaviour scores did not decrease, it is promising that the parents with a learning disability had significantly reduced parental stress scores. As discussed earlier, McLean (1976) proposed that a vicious cycle of stressful child-parent interactions occurs where the affective behaviour of parents in turn leads to children having difficulty regulating their own behaviour. As one of the factors in this cycle (i.e. parental stress) improved after the group, it may be likely that over time this will have a positive effect on child behaviour, which is perhaps more resistant to change in a short time-period.

The non-significant decrease in child behaviour problems is not unusual (Doubleday, 2004). Hartman et al. (2003) highlighted that, in general, approximately one-third of children remain in the clinically significant range at parenting group follow-ups and improvements are also unlikely for first-time group attendees. Many of the parents in both groups noted that the techniques discussed e.g. praising and ignoring, were approaches that they had 'never' tended to do and that it was difficult to break old habits such as parent-child escalation traps. Budd & Greenspan (1985) concluded that parent training for parents with learning disabilities should run for longer than typical programmes for parents without learning disabilities. Fortunately the groups with parents with learning disabilities continued to run after the study period, which will allow the parental group intervention to be evaluated over a longer period. The results

in this study may reflect the time-limited nature of the research period rather than ineffectiveness of the training per se. Research suggests that training beyond mastery or “overtraining” (Sutherland & MacKintosh, 1971) may be necessary for generalising and maintaining parenting skills (Feldman et al., 1986). Similarly, McGaw (1996) notes that parents with a learning disability often require support until their children reach adulthood.

**Hypothesis B4: The positive parenting group for parents with a learning disability will increase social support scores and perceived helpfulness of supports.**

Hypotheses B4 was confirmed as, after participation in Triple P, the parents with a learning disability reported a significant increase in the number of social supports. This increase in support was maintained at six-week follow-up. Group Triple P focuses on encouraging parents to increase their social supports and/or to make use of the supports already available to them. The increase in number of supports was partly due to the ‘parenting groups’ now being included. At both groups parents were observed to be making friendships and organising social meetings outside the group. ‘Meeting other parents’ was the most common positive comment given about the groups on the satisfaction form. Wahler & Afton (1980) suggest group treatment takes on greater importance when social isolation is identified. While the number of supports increased, this study raised the notion that *decreasing* supports may in fact be helpful in some cases. One parent had been advised by professionals that her partner was not helpful and despite the mother rating him highly on the FSS, he was perceived by the professionals involved to have a negative effect on her psychological

well-being. A decrease in number of supports may, therefore, have been evaluated negatively without careful consideration of personal circumstances. This suggests that 'positive decreases in support' should perhaps be included as an item in formal assessments.

**Hypothesis B5: The positive parenting group for parents with a learning disability will increase levels of praise and effective child behaviour management strategies.**

Hypothesis B5 was confirmed as responses generally improved on the parenting skills assessment. Although the parents with a learning disability still admitted to occasionally shouting at their children and not following threatened punishments through, they showed an increase in the use of praise, time-out, consequences and ignoring minor behaviour problems. As with other questionnaire-based studies of parenting style (e.g. Tymchuk et al., 1990) this does not necessarily mean the parents were actually applying the strategies at home. The treatment was limited to group intervention at community locations and many authors have noted that, for parent training to be effective for parents with learning disabilities, the skills may be better taught in the environment where they are to be used i.e. the parent's home (Espe-Sherwindt & Kerlin, 1990, Feldman et al., 1992, Tymchuk & Andron, 1992, Whitman & Accardo, 1990). Tymchuk & Andron (1994), however, note that while providing services in the home appear to be more successful for some aspects of childcare, offering a group at a centre not only provides a social environment but also friendship opportunities. They suggest that the most optimal condition is to combine group-based teaching with occasional or follow-up home visits.

McGaw (2000) noted, however, that the combination of group and home intervention requires substantial resources which are often not readily available to service providers in the UK. That study found only two out of sixteen service providers were providing both home based and group teaching. Furthermore, Llewellyn, McConnell, Russo, Mayes & Honey (2002) highlighted the realities of home-teaching they experienced such as numerous and frequent noisy distractions (e.g. children present, telephone ringing), interruptions from outside (visitors, deliveries) and being absent for part of the session while attending to domestic tasks. They also had the difficulty of the parent identifying with the professional as a friend rather than a service provider and airing personal issues before concentrating on the task in hand. Furthermore, home-teaching did not lead to improved attendance (an average of three appointments were missed per family). While time restrictions of the present study did not permit the researcher to conduct home-visits, part of the agreed remit of the Community Learning Disability Nurse attending the groups was to facilitate generalisation of the use of the skills at home. Generalisation was also facilitated in the group by encouraging the parents to use real-life examples for discussion/role-play and asking them to inform the group of their use of the strategies out-with the session, which the therapist always reinforced by giving this matter time and praise<sup>8</sup>.

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<sup>8</sup>This 'train to generalise' technique is recommended by Stokes & Baer (1977) as an effective generalisation strategy.

**Hypothesis B6: Parents with learning disabilities will report high levels of satisfaction with the group.**

Hypothesis B6 was confirmed as, despite the non-significant results on some of the measures, the Triple P was rated very highly in terms of consumer satisfaction. The majority of the parents found the group useful, relevant, easy to participate with and understandable. They liked the way the information was given and rated feeling more able to cope with their children's behaviour. Similarly, McGaw (1999) and McGaw et al. (2002) found that following group training programmes, parents with a learning disability made new friends, became less reliant on professionals, had improved self-esteem, engaged in new activities and had more positive feelings towards their children. It may be, therefore, that the measures used in the study did not reflect what the parents had gained from the group. Most of the parents with learning disabilities noted that they had never attended a parenting group before and particularly liked the group as it was small in size and 'friendly'. One parent commented that she would not have attended if the group had been larger and spoke of previous experience of panic attacks in larger group situations. The satisfaction of the parents with learning disabilities suggests small specialist groups for this population are appropriate. The parent with a learning disability who 'strongly disagreed' with some of the statements was offered individual appointments after completion of the study as additional issues had emerged with regards to her self-esteem, care of her children and own childhood experiences. She was particularly dismayed at her parenting abilities with her two teenage daughters and believed the Triple P was only suitable for younger children despite frequent discussions of the appropriate use of the strategies (e.g. pocket-money as a consequence) with teenage children. She also complained of feeling less

able than the other members in the group although her cognitive assessment results showed she had the highest intellectual functioning of the PART B participants (IQ=73).

#### **4.4. STRENGTHS OF STUDY**

In the current study, all participants had IQ's assessed and a structured, empirically evaluated parenting training programme was employed (i.e. Triple P). This appears to be the first paper (and therefore, a pilot study) to directly compare the effect of the same structured parenting training programme used with both a learning disabled and non learning disabled group. This study employed a control group for the PSI (Feldman et al., 1997 compared scores with published norms) and FSS (Llewellyn et al., 1999 did not have a control group). Previous papers have also tended to restrict their focus to increasing positive play, praise and affection with young children, ranging from 6 month old babies (Feldman et al., 1986) to an upper age of five (e.g. Peterson et al., 1983). The intervention in the current study focuses on both positive parenting and discipline strategies and has the virtue of assessing the effect of group training on parents with children from age 2 to 14 years old. Socio-economic status of both groups of parents was also coded by means of a deprivation index score. This was a more sophisticated measure as compared to Feldman et al.'s (1986) observation that the control parents 'appeared' (p. 25) to be of middle socio-economic class.

This is the first study to have systematically examined parental stress and general emotional well-being of parents with a learning disability and behaviour of their children. Feldman et al. (1997) restricted their study to parental stress and was problematic due to the upper inclusion IQ of 80 and therefore, 'not all the parents met DSM-IV diagnostic criteria for learning disabilities- IQ<70-75' (p. 474). The upper

IQ of 75 in the current study was chosen to allow comparability with research and to access as many parents with intellectual disabilities as possible. The confidence limits of the participants with the IQ's of 75 and 73 placed these individuals within the learning disabled category, however, researchers across the field may attempt to be consistent in inclusion criteria of IQ<70 in the future. This may continue to be problematic as McGaw's (2000) unique Special Parenting Service in Cornwall accepts parents of IQ 55-85. It is also interesting that the parent with an IQ of 73 noted feeling less able than the rest of the group and inclusion in a general parenting group is only likely to have caused further difficulties and non-attendance.

A significant strength of the study was the fact that cognitive assessments rather than the 'social systems' approach used in other studies were completed to confirm inclusion criteria. Had the social systems approach been used (inclusion based on being known to the learning disability field) three participants would have been incorrectly included (full scale IQ's found to be 80, 83 and 85).

#### **4.5. LIMITATIONS OF STUDY**

##### **4.5.1. Sample size, attendance and participants**

The study was limited in terms of the small sample size of parents with a learning disability and did not meet Cohen's (1992) criteria that for a large effect size, 26 treatment participants are needed to achieve a power of 0.8. The number of parents with a learning disability in PART B, however, was higher than some previous intervention studies with parents with learning disabilities (e.g. Feldman et al., 1989 was based on three parents). Information about the pilot study was distributed to over 230 professionals across the Tayside area and the amount of referrals may therefore

reflect the small population of parents with learning disabilities in this area. Due to the small sample this study was based on it is possible that the tests of those hypotheses that were not confirmed had insufficient power to achieve statistical significance. However, although in PART A power for the tests for the PSI and HADS was extremely small (0.12 and 0.05 respectively), the effect sizes were also very low (0.02 and 0.00 respectively). In PART B group intervention did not result in significant improvements in anxiety/depression and child behaviour. For the parents with a learning disability effect size<sup>9</sup> of the HADS was 0.12 (power 0.09)<sup>10</sup> and for the Rutter Child Behaviour Scales, 0.26 (power 0.15). With such low effect sizes a very large sample would be needed to achieve a power of 0.8. The tables provided by Clark-Carter (2004) suggest that 700 parents with a learning disability would be required to achieve this power level for the effect size found with the HADS and 160 for the Rutter Behaviour Scales. As these numbers are likely to be very difficult to achieve with this population, effect size may be improved in future studies by altering the design of this pilot study, as discussed throughout this section (e.g. running group for longer period of time).

Attendance at the groups was problematic and across both groups of parents only three attended every session. It is interesting that of the nine parents with a learning disability who attended, five of these were transported by the Community Learning Disability Nurse. It is likely that attendance would have been even less without this assistance. Likewise increased transport may have led to improved attendance.

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<sup>9</sup> Calculated using Clark-Carter's (2004) formula that to convert an effect size from a within-subjects z score, divide z by square root of N (p. 431).

<sup>10</sup> As per within-subjects power tables from Clark-Carter (2004, p.588).



Several potential referrers did telephone the researcher enquiring about transport, expenses and crèche facilities and subsequently did not refer when they discovered that these would not be provided. One parent from Part A of the study who was very keen to attend the group was unable due to lack of childcare. This pilot study has, therefore, raised practical implications for running parenting groups and suggests there may be a much larger population of parents with a learning disability requiring help who were not accessed. Future research may attempt to increase numbers and therefore, the power of the study perhaps by providing assistance with psychosocial factors such transport/childcare (which Doubleday, 2004 notes are significantly related to outcome) and/or conducting regional trials.

The study was also limited to mothers (with the exception of one father in the control group). This was not deliberate on the part of the researcher and simply reflected referrals received. Only three of the eighteen parents with a learning disability were married and unfortunately, none of the fathers attended the group. Tymchuk (1990b) notes that most studies purporting to be about parents with a learning disability in fact only included mothers with a learning disability. The majority of studies have also mainly included parents with very young children and the parenting of adolescents by this population has received limited attention (Tymchuk & Andron, 1994). Although the child age inclusion criteria for this study was under 16 years of age, the majority of the sample had younger children. Interestingly, the mother with teenage daughters was having particular difficulty as noted earlier. This is consistent with the literature that parents with a learning disability find the demands of adolescence particularly difficult to cope with (Whitman & Accardo 1990), possibly due to the child's cognitive ability exceeding the parents.

#### **4.5.2. Recruitment method**

A common methodological weakness underlying intervention programmes for parents with a learning disability, which is also applicable to this study, relates to the recruitment process itself. It has been noted that recruiting families already known to services is open to criticism for using an unrepresentative “skewed population”. (Tymchuk et al., 1991). There are likely to be many learning disabled families who are parenting at a competent level who have not come before authorities or are unknown to services (Llewellyn, 1990). However, given the nature of the population and lack of regional statistics, it was not thought appropriate to advertise the group by means of leaflets, given the possibility that the interested parents may not be able to read. For the same difficulties, neither would it have been appropriate to mail letters to parents with a learning disability in the community. Hence it was decided that it would be more appropriate to have a person already known to the parent approaching them. This has also been suggested (Booth & Booth, 1993b) as an ethically sound means of gaining consent: the research is introduced by someone the parents know; it prevents agencies from having to release confidential information and it makes it easier for the parents to refuse.

#### **4.5.3. Assessment Measures**

No difficulties were encountered with the assessment measures, which is likely to be due to the fact that, like other studies reporting no difficulties (e.g. Feldman et al., 1997), they were verbally administered by the researcher, the language was simplified and visual aids were provided to help with the response. It is to be noted, however, that the measures used (with the exception of preliminary work with the HADS) have not been standardised or psychometrically evaluated with people with a learning

disability. This reflects a general limitation in terms of assessments for people with a learning disability (Tymchuk & Andron, 1994) as no standardised assessments appear to exist for assessing parenting by this population. English (2000) reported that 18 out of 23 professional groups said they did not use a formal assessment tool when working with parents with learning disabilities. Holburn et al. (2001) note that standards and judgements of parenting continue to be subjective in some cases. There is a critical need to examine the psychometric properties of parenting measures such as the parenting stress index with parents with learning disabilities.

An additional limitation with regard to the assessments was that the adapted measures were not piloted before use. It would have been extremely difficult, however, to find a separate set of parents with a learning disability with whom to conduct this. While the parents were asked informally about the measures, the results of which indicated satisfaction, it may have been helpful to have devised a short evaluation form assessing ease of completion of the adapted measures. A future study may also concentrate on assessing the reliability of the adapted parenting measures used in this study.

As the control parenting groups were completed before the learning disabled group took place and the current study was proposed, the control group completed the non-adapted measures. Future studies of this nature may, therefore, be improved by administering the adapted measures to both the learning disabled and non learning disabled groups to ensure homogeneity of assessments. While it would have been helpful to administer the adapted version to a small group of the parents without a learning disability to examine the correlation of the two measures, this was not

possible as the parents of the clinical control data had been discharged from the service prior to the study.

#### **4.6. REFLECTIONS ON TRIPLE P**

The results of this study suggest that the Triple P package used in the current study may not be the most effective choice of intervention for parents either with or without a learning disability. Even when significant decreases in scores were found, the post-group scores remained above clinical cut-off levels for both the groups and in particular the intervention had no effect on child behaviour scores. Where significant results were found (e.g. increases in social support) this is likely to be a reflection of attending a group rather than the actual Triple P package per se. This does raise the question of whether the group Triple P package should continue to be used with these parents and has certainly demonstrated the need to research the use of other forms of parent training (e.g. individual work/combined individual and group work) and consider revisions to the group Triple P package for use with parents with a learning disability. Based on the parent satisfaction measures the parents did report enjoying the video and having clear, illustrated hand-outs. Other hand-outs such as behavioural charts also had to be adapted and the parents had no difficulties with the simplified charts. After having piloted the adapted Triple P in this study the researcher did, however, recommend that for future use with this population each session should cover just one parenting idea or strategy (e.g. managing misbehaviour is covered in session 3 in the Triple P and it was recommended that ignoring, consequences, giving instructions etc. should be taught as one strategy per session). This does, however, mean that groups would need to run for a longer period of time. While the video was also helpful in terms of modelling the parenting strategies, some of the language used

in the video was quite complex and again each strategy was covered very quickly. It would be ideal to have available a parenting video designed specifically for parents with a learning disability.

#### **4.7.SERVICE IMPLICATIONS**

Referrals to the study were received from both child and learning disability services in health and social care services. The study highlighted that parents with a learning disability are referred to different specialities in Tayside, but between which there is very little co-ordination or liaison about this population. The failure of services to attend adequately to the needs of both children and their parents has featured regularly in user feedback (Griggs, 2000). Griggs (2000) highlighted:

Most Clinical Psychologists remain firmly located within fragmented services engaging with a defined client group and have largely missed the opportunity to ensure that their wider systemic perspectives influence explicit service delivery models (p. 8)

Fragmented clinical psychology services are not consistent with the Department of Health's (1991) requirement (as per the Children Act, 1989) for services to work together to meet the needs of children and their families. Collaboration between child and adult services (including adult learning disability services) is, therefore, required to ensure that both the needs of children and parents are identified and the family are offered an integrated package of assessment and treatment. McGaw (1996) notes that difficulties will emerge when a professional adopts an adult or child-centred approach to case-management with the exclusion of the other.

The Jigsaw of Services document (DOH, 2000) highlights the need to have a co-ordinator for the many different agencies involved with parents with a learning

disability. Prior to this pilot study the professionals working with these parents would not have had access to a specialised service to whom they could refer. As an outcome of the study the researcher aims to adopt the model of Bristol NHS Trust, who have collated a list of the key people who might be useful in being involved in helping parents with a learning disability. The current study also resulted in the establishment of a co-ordinated parenting network group for professionals working with parents with a learning disability. Woodhouse, Green & Davies (2001) suggest the Cornwall Parenting Service, which is dedicated solely to working with parents with a learning disability, remains the ideal service model for this population.

#### **4.8. ADDITIONAL DIRECTIONS FOR FUTURE RESEARCH AND SERVICE IMPROVEMENTS**

McGaw & Sturmey (1994) suggest there is a need to find ways of identifying parents with learning disabilities who are not already known to services. Preventative moves should also be taken to identify parents *before* crises levels are reached or inadequate care is suspected (Sheerin, 1998). McGaw (1996) states that the early identification of parents with learning disabilities is essential to good working practice. Further research is also required on how parents with a learning disability cope with teenage children, as very little is known about this area. Certainly, the parent in this study who reported most difficulty was the mother of teenage daughters. Glaun & Brown (1997) suggest our challenge is to find ways of providing support in a 'competence-promoting' (Tucker & Johnson, 1989) manner, without destroying self-esteem and trust. Several researchers have also noted a lack of literature where the voices of parents with learning disabilities are heard (e.g. Booth & Booth, 1992, Llewellyn,

1992, 1994) in relation to issues such as specialist v generic parenting services and their experiences of parenting with a learning disability.

The training needs of professionals need to be identified across services. While studies have been conducted in England examining the professional services available to parents with a learning disability (e.g. Genders, 1998, McGaw, 1998), there appears to be no such studies in Scotland. Green & Vetere (2002) noted that many professionals have had no training on the needs of parents with a learning disability and lack knowledge and understanding of these families. Feldman (1994, 2002) suggests that a good deal of work is needed to educate professionals about the many factors, in addition to intellectual ability, which affect parenting and that many of these parents are quite capable of learning to provide acceptable childcare. Services also need to acknowledge their own assumptions and anxieties about working with these families (Chinn, 1996).

#### **4.9. CONCLUSIONS**

The results of PART A of this study have shown that parents with a learning disability are experiencing a comparable amount of parental stress, anxiety, depression and child behaviour problems as parents without a learning disability, despite only the latter group historically having been offered group intervention in the Tayside area, a situation also likely reflected in other areas. Unfortunately the intervention employed in PART B of this study had rather mixed results, with many scores either remaining unchanged after treatment or having decreased but remaining above clinical cut-off levels. This does call into question the benefit of group Triple P with these parents. Having identified problematic levels of parental stress, anxiety/depression and child

behaviour scores, it is therefore now time to continue to focus on providing the most suitable form of intervention for parents with a learning disability. The benefit of being able to meet other parents was, however, highlighted by these parents in this study and should not be understated for this often socially isolated group. It may be that long-term and more intensive parenting intervention combining both home and group intervention is, therefore, necessary for this population, which may have more promising results, particularly for child behaviour difficulties. Attention to socio-economic stressors may also be necessary in order to see a reduction in HADS scores. Having identified a small population of parents with a learning disability in Tayside with significant mental health problems, there is a need to investigate the services available for these parents, training needs of professionals working with them and co-ordination between child, adult and learning disability services.



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## APPENDICES

## Appendices

**Appendix 1:** Ethical approval for study from Tayside Ethics Committee

**Appendix 2:** Letter explaining research and referral form

**Appendix 3:** Parent Information Booklet

**Appendix 4:** Consent form

**Appendix 5:** Caldicott Approval for access to control data

**Appendix 6:** Confirmation from ethics to widen inclusion criteria

**Appendix 7:** a) Family Background Questionnaire for parents without a learning disability

b) Family Background Questionnaire for parents with a learning disability

**Appendix 8:** a) Theoretical model for short-form Parental Stress Index

b) Original Parental Stress Index

c) Adapted Parental Stress Index

**Appendix 9:** a) Original Hospital and Anxiety Depression Scale

b) Adapted Hospital and Anxiety Depression Scale

**Appendix 10:** a) Revised Rutter Child Behaviour Scales

b) Adapted Rutter Child Behaviour Scales

**Appendix 11:** a) Supports included in Family Support Scale

b) Family Support Scale

**Appendix 12:** Parenting Skills Assessment

**Appendix 13:** a) Satisfaction questionnaire for parents without a learning disability

b) Satisfaction questionnaire for parents with a learning disability

**Appendix 14:** Outline of Triple P programme

**Appendix 15:** a) Original Triple P overhead

b) Adapted Triple P overhead

**Appendix 1:** Ethical approval for study from Tayside Ethics  
Committee

Ms Julie Cottrell  
Trainee Clinical Psychologist  
Centre for Child Health  
19 Dudhope Terrace  
DUNDEE  
DD3 6HH

Date 19 December 2003  
Your Ref  
Our Ref NFB/FB/211/03  
Enquiries to Mr Nigel F Brown  
Extension 32701  
Direct Line 01382 632701  
Email [nigel.brown@tuht.scot.nhs.uk](mailto:nigel.brown@tuht.scot.nhs.uk)  
or  
[fiona.bain@tuht.scot.nhs.uk](mailto:fiona.bain@tuht.scot.nhs.uk)

Dear Ms Cottrell

**Ref: 211/03 An evaluation of a positive parenting group for parents who have a learning disability**


I refer to your letter which was received here on 13 November 2003 with which you enclosed Parent Information Leaflet version 2, dated 12 November 2003, the GP letter and the Evaluation Form. Having received a copy, you will know that I have received confirmation from Dr Walker that the parents (patients!) involved in this study will be able to give their own consent to participate and I am therefore pleased to confirm approval on behalf of the Tayside Committee on Medical Research Ethics subject to the following conditions. Please note that some of these are relatively new conditions that reflect new Governance Arrangements.

*Conditions of Approval:*

- The research may proceed only when you are also in possession of a final approval letter from the NHS Tayside R & D to whom I am copying this letter.
- You should follow the protocol agreed and advise the Committee of any proposed amendments – no significant changes to the protocol should be made without Ethics Committee approval.
- You must promptly inform the Ethics Committee of deviations from or changes to the protocol which are made to eliminate immediate hazards to the research subject; of any changes that increase the risk to subjects and/or affect significantly the conduct of the research; all adverse events that are both serious and unexpected; new information that may adversely affect the safety of the subjects or the conduct of the research; if the research is abandoned for any reason.
- Each research proposal will be subject to a follow-up review and may be selected for a monitoring visit on behalf of the Tayside Trusts.
- You must start the project within three years of the date approval is given or the approval expires; extensions can be applied for.
- You are required to provide an annual update on the progress of the study and notify the Committee of its termination.

Yours sincerely

 **LREC ADMINISTRATOR**

 Mrs K Coll, NHS Tayside R&D

Members: Dr J Davidson (Chairman); Mr P K Brown; Ms D Campbell (Vice Chairperson); Dr C Jackson; Dr F Daly; Mr A S Jain; Miss E S Macallan; Dr S MacAndrew; Mr A MacConnachie (Medical Advisor); Mr G MacLaren; Dr W Stevenson; Dr M A R Thomson; Mrs F Valentine; Mrs L Van Aalten.  
Deputies: Dr D Cuthbertson; Dr E Mitchell; Ms M Paterson; Dr D Carson  
Administrator: Mr N F Brown



LC/LH

06 January 2004

Ms Julie Cottrell  
Clinical Psychology Department  
Centre for Child Health  
19 Dudhope Terrace  
DUNDEE  
DD3 6HH

Dear Ms Cottrell,

**R&D Project: 2003LD03**

**Title: An evaluation of a positive parenting group for parents who have a learning disability.**

**LREC Ref: 211/03      LREC Final Approval Date: 19/12/03**

**Funding: Unfunded study**

**NHS Support Required: £572**

The above project has been registered on the NHS Tayside R&D database, as required by the Research Governance Framework. Full LREC approval has been obtained and there are £572 of NHS Support costs associated with this research project.

NHS Tayside has no objection to the project proceeding, provided all necessary approvals are in place and all amendments to the protocol, personnel involved and funding be notified to the R&D office and all appropriate personnel.

It is important to note that all research must be carried out in compliance with the Research Governance Framework for Health & Community Care and the new EU Clinical Trials Directive.

Kind Regards,

Elizabeth Coote  
Non-Commercial  
Research & Development Manager

c.c. Mr Nigel Brown

R&D Office, Level 9, Ninewells Hospital & Medical School, Dundee, DD1 9SY

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## **Appendix 2:** Letter explaining research and referral form

Clinical Psychology Department  
Wedderburn House  
1 Edward Street  
Dundee  
DD1 5NS

Telephone: Dundee (01382) 346025

Dear Sir/Madam

**RE: RESEARCH PROJECT- AN EVALUATION OF A POSITIVE PARENTING GROUP FOR PARENTS WITH LEARNING DISABILITIES**

As a Trainee Clinical Psychologist on the East of Scotland (University of Edinburgh) training course, I am required to undertake a research project for my final year. I am interested in setting up and evaluating a parent-training group for parents with learning disabilities in the Tayside Area, including those in the borderline range of functioning.

I am currently seeking referrals for participation in this study. If you are working with parents with a learning disability I would be grateful if you could let them know about this study. Should they express an interest in joining the study I have enclosed a patient information booklet to be given to them (please read to the person if need be). If they would like to participate in the study I would be grateful if you could send me contact details. Please make sure to check that your patient is happy for their name and address to be sent to me by asking them to sign the consent statement on your referral form. As I will be meeting with the parents individually before the group starts they will have opportunities to ask questions and find out more about the group which may help them decide whether to join or not.

Inclusion for this study requires the participant to have an IQ between 60 and 75 (mild learning disabilities), caring for at least one child below the age of 16 (part or full time) with difficulties in child behaviour management. As the group will focus on positive parenting skills it would not be appropriate to make a referral where needs are centred around issues such as nutrition, hygiene, domestic or safety issues. The topics that will be covered in the Triple P programme are as follows:

- Session 1: Positive Parenting
- Session 2: How to help children develop
- Session 3: How to deal with misbehaviour
- Session 4: Planning Ahead (Family Survival Tips)
- Session 5: Review and Programme close



Exclusion criteria includes active or pending child care or court proceedings and any condition that may interfere with participation (e.g. severe drugs and alcohol problems/uncontrolled mental illness).

I hope to start interviewing participants in January 2003 and would be grateful if **you could return the referral form as soon as possible, and no later than 26<sup>th</sup> January 2003.** The research will be run under the supervision of Dr Sarah Broxholme, Clinical Psychologist. The project has received ethical approval from NHS Tayside Ethics Committee. I look forward to hearing back from you with any appropriate referrals and signed consent from your patient. Please do not hesitate to photocopy the referral form if you wish to refer more than one person. Your help is much appreciated.

Yours Faithfully  
Julie Cottrell  
Trainee Clinical Psychologist

# CLINICAL PSYCHOLOGY DEPARTMENT

## LEARNING DISABILITIES SECTION - WEDDERBURN HOUSE

### REFERRAL FORM FOR POSITIVE PARENTING GROUP

**PATIENT DETAILS** - (This Information is essential for processing the referral, please complete fully)

**Name:** ..... **DOB:** ..... **CHI:**.....

**Address:** .....

.....**TELEPHONE NUMBER:**.....

**GP name & address:** .....

**Other agencies involved:** Psychiatrist ☐ .....  
(please tick as appropriate) Community Nurse ☐ .....  
and fill in names if known) Care Manager ☐ .....  
Keyworker in residential setting ☐ .....  
Keyworker in ARC ☐ .....

**Name & designation of referrer:** .....

**Address/Tel No:** .....

**Reason for referral to parenting group:**.....  
.....  
.....  
.....

**Date of referral:** ..... **Name of Psychologist:** Dr Sarah Broxholme/Julie Cottrell

**\*\*\* THIS SECTION MUST BE COMPLETED\*\*\***

**PATIENT'S CONSENT** - I agree for my details above to be sent to Julie Cottrell so she can contact me about the parenting group

**PATIENT'S SIGNATURE:**.....

Please return to: Julie Cottrell  
Clinical Psychology Department  
(Learning Disabilities Section)  
Wedderburn House  
1 Edward Street  
DUNDEE DD1 5NS  
(Tel: 01382 346025)

## **Appendix 3:**    Parent Information Booklet

# PARENT INFORMATION LEAFLET

*Evaluation of a positive parenting group  
for parents with learning disabilities*



**TAYSIDE AREA CLINICAL  
PSYCHOLOGY DEPARTMENT**

## **What is this booklet about?**

We are asking you to take part in a project. We believe that it could be of importance. However, before you decide to take part we need to be sure that you understand why you are doing it. We also need to make sure you know what it would involve if you agree.

We are therefore giving you the following information. Read it (or listen) carefully and be sure to ask any questions you have. You can talk about it with other people, such as your doctor. We will do our best to explain and to give any further information you may ask for now or later. You do not have to make a decision straight away.

## **Who is involved with the project?**

My name is Julie Cottrell, a Trainee Clinical Psychologist and the main project leader. The project is supervised by Dr Sarah Broxholme, Clinical Psychologist.

## **What is the project about?**

I am running a parenting group. The group will talk about the things you like about being a parent. We will also talk about the things you sometimes find difficult about being a parent.

In the group you will be able to talk to other parents about these problems. They have probably come across the same difficulties as you. It is important to remember that most parents find that it can sometimes be difficult looking after children.



As the group leader I will try to help you with these problems. We can talk about new things to try with your child that might help both you and your child to feel better.

If you wish to join the group I will be helping you to fill out a survey at the start and end of the group. This lets me see if the group has helped you.

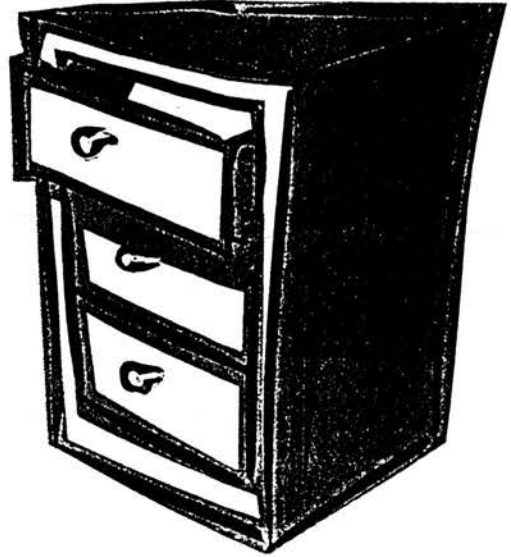
The results will be used when the project is written but your name will be taken out.



We will find out if the group has helped you looking at your answers to the survey. Your answers will let us know whether you liked the group, how sad or worried you have been feeling and the difficulties you may be

having with your child. Your child will not be asked to fill in anything or to come to the group.

Nobody will be allowed to look at your answers to the survey or information about you except my supervisor and me. All information will be locked in a filing cabinet.



You do not have to say 'yes' to joining the group. It is okay to say that you don't think you would like this type of group. It is also okay to come and try the group and if you don't like it to stop coming **at any time**

during the group.

**It is your choice....!!!**





If you choose to join the parenting group I may have to find out more about your learning disability. This means asking you to do some puzzles with me. You can also say 'no' to this. Remember...it is your choice.

If you would like to join the parenting group please let the person who gave you this booklet know. Your helper will ask you to sign a form so that I know you are happy about your name and address being sent to me.



I will write a letter to you when the group is ready to start and let you know where and when it will be.

If you want to ask me any questions or talk to me about the research project you can contact me at the address below:

**Julie Cottrell**  
**Clinical Psychology Department**  
**Wedderburn House**  
**1 Edward Street**  
**Dundee**  
**DD1 5NS**  
**Telephone: Dundee (01382) 346025**

## Appendix 4: Consent form

**CONSENT FORM - AN EVALUATION OF A POSITIVE PARENTING  
GROUP FOR PARENTS WITH LEARNING DISABILITIES**



- I would like to join a parenting group. I have read the information booklet about this group.
- I understand that I can drop out of the group at any time. I don't have to give a reason for this to anyone.
- I know that I can ask any questions about this group at any time.
- I understand that information about how I have been getting on in the group will be discussed with Dr Sarah Broxholme (Clinical Psychologist).
- I understand that it is up to me whether information about how I have been getting on in the group is sent to my Doctor and the person who referred me.
- I understand that my name will not be included when the project is written.
- I understand that Julie Cottrell might want to find out more about my learning disability. I agree to take part in a test that will help decide if this group is suitable for me. I understand this will involve doing some puzzles.

**PRINT NAME:**

**SIGN NAME:**

**DATE:**

## **Appendix 5:** Caldicott Approval for access to control data

Information Security  
Ashludie Hospital  
Monifieth  
Angus  
DD5 4HQ  
Telephone Number 01382 527920  
Fax Number 01382 423082  
www.nhstayside.scot.nhs.uk



Julie Cottrell  
Trainee Clinical Psychologist  
Clinical Psychology Department  
Wedderburn House  
1 Edward Street  
Dundee  
DD1 5NS

Date 4<sup>th</sup> February 2004  
Your Ref  
Our Ref Caldicott/access/JC040204  
Enquiries Peter McKenzie  
to  
Email information.security@thb.scot.nhs.uk

### **Positive Parenting Group Project**

Attached to this letter is copy of the completed Confidentiality Statement giving Caldicott Guardian approval for access to patient records in support of the study as submitted.

Thank you for your co-operation in providing us with the information requested by us in this process.

Should any issues or queries arise during the study, relating to the accessing of patient records, please contact me.

Peter McKenzie, Information Security Officer

Copy:



Headquarters  
Ashludie Hospital, Monifieth, Angus, DD5 4HQ

Chairperson, Mr Murray Petrie  
Head of Services, Mr Daniel McLaren

**User Details**

Name: Julie Cottrell  
Position: Trainee Clinical Psychologist  
Organisation: Clinical Psychology  
Address: Wedderburn House  
1 Edward Street  
Dundee  
DD1 5NS  
Tel: 01382 346025

**Sponsor Details**

Name: DR. PHYLLIS WALKER  
Position: CONSULTANT  
Organisation: T.P.E.  
Address: CARRSVIEW CENTRE  
DUNDEE  
Tel:

**Data Protection Reg. No. :**

**Data Requested :** outcome measures (ie Parental Stress Index, Hospital Anxiety & Depression Scale, Rutter behaviour scales) for parents referred to a parenting group run by Child Clinical Psychology department to use as control data for my doctoral thesis.

**Co-Users of the Data :**

**Intended use of data (inc. publications) :**

Clinical Psychology Doctoral Thesis

**Period for which Data to be Retained :** Jan 04 - Oct 04

**User's Declaration**

I declare that I understand and undertake to abide by the rules for confidentiality, security and release of data received from NHS Tayside.

Signature

Date 23.01.04

**Sponsor's Declaration** (to be signed by a consultant if patient data is requested and the applicant is not of that status or is not medically qualified)

I declare that the above named user of the data is a bona fide worker engaged in a reputable project and that the data requested can be entrusted to this person in the knowledge that they will conscientiously discharge their obligations in regard to confidentiality of the data.

Signature

Date 29/1/04

On completion, please return this form to:

The Information Security Officer  
NHS Tayside  
Ashludie Hospital  
Monifieth  
Dundee  
DD5 4HQ

For NHS Tayside use only

Release authorised by

Date

2/2/04

Ref.No.



**Appendix 6:** Confirmation from ethics to widen inclusion criteria



Tayside Committee on Medical Research Ethics  
Level 9  
Ninewells Hospital & Medical School  
DUNDEE  
DD1 9SY  
Telephone Number: 01382 632701  
Fax Number: 01382 496207  
[www.nhstayside.scot.nhs.uk](http://www.nhstayside.scot.nhs.uk)



Ms Julie Cottrell  
Trainee Clinical Psychologist  
Centre for Child Health  
19 Dudhope Terrace  
DUNDEE  
DD3 6HH

Date	1 March 2004
Your Ref	
Our Ref	NFB/FB/211/03
Enquiries to	Mr Nigel F Brown
Extension	32701
Direct Line	01382 632701
Email	<a href="mailto:nigel.brown@tuht.scot.nhs.uk">nigel.brown@tuht.scot.nhs.uk</a> or <a href="mailto:fiona.bain@tuht.scot.nhs.uk">fiona.bain@tuht.scot.nhs.uk</a>

Dear Ms Cottrell

**Ref: 211/03 Emotional and social lives of parents with learning disabilities and the effect of a positive parenting programme on psychological wellbeing – a pilot study**

Thank you for your email of 18 February 2004. I have to say that Gus had mentioned this to me, but we were slightly at cross-purposes and I had not realised that he was talking about a further two parents. I am pleased to formally confirm, therefore, the inclusion of the two that you mentioned, ie, the parent with the full-scale IQ of 57 and the other one with the IQ of 54, which means of course that the inclusion criteria is widened to 54-75.

Yours sincerely

**Nigel F Brown**  
**LREC ADMINISTRATOR**



Members: Dr J Davidson (Chairman); Mr P K Brown; Mrs D Campbell (Vice Chairperson); Dr C Jackson; Dr F Daly; Mr A S Jain; Miss E S Macallan; Dr S MacAndrew; Mr A MacConnachie (Medical Advisor); Mr T McEwan; Mr G MacLaren; Dr W Stevenson; Dr M A R Thomson; Mrs F Valentine; Mrs L Van Aalten.  
Deputies: Dr D Cuthbertson; Dr E Mitchell; Ms M Paterson; Dr D Carson  
Administrator: Mr N F Brown

**Appendix 7a:** Family Background Questionnaire for parents without a learning disability

## FAMILY BACKGROUND QUESTIONNAIRE

Name.....

Address.....

.....Postcode.....

Telephone contact number.....

Today's date ...../...../.....

### The Family

1. Child's name.....

2. Child's sex

Male

Female

3. Child's age today.....(years)

4. Child's date of birth...../...../.....

5. Your relationship to this child

Mother (biological or adoptive)

Father (biological or adoptive)

Step-mother

Step-father

Foster mother

Foster father

Other (describe).....

6. Your current marital status

Married

Separated

Cohabiting

Divorced

Widowed

Single

7. At present who lives at home with your child (e.g. parents, siblings, grandparents) ?

NAME	AGE	SEX	RELATIONSHIP TO CHILD

8. Which best describes the household in which your child is presently living?

Original family (both parents still present)

Step-family (two parents, one being step-parent)

Sole parent

Other (please describe).....

## Your Education and Employment

9. Your highest level of education

Less than secondary  
Secondary  
Trade/apprenticeship  
Diploma/College qualifications  
University degree  
Post graduate

10. Your partner's highest level of education (if applicable)

Less than secondary  
Secondary  
Trade/apprenticeship  
Diploma/College qualifications  
University degree  
Post graduate

11. Are you currently in paid employment?

Yes                                      how many hours per week?.....  
No

12. Is your partner currently in paid employment

Yes                                      how many hours per week?.....  
No

## Your Health

13. In the last 6 months have you or your partner sought professional assistance from any of the following?

	Self		Partner	
	Yes	No	Yes	No
Psychologist				
Psychiatrist				
Counsellor				
Social Worker				
Other professional				

**Your Child’s Health**

14. Does your child experience any of the following?

	Yes	No
A vision or hearing impairment		
A severe chronic illness		
A physical disability		
An intellectual disability		
A developmental delay		
Symptoms in line with those of ADHD		
Autism		
A restrictive diet advised by a health professional		

15. Is your child having any regular contact with another professional for emotional or behavioural problems?

No  
Yes  
(please give details).....

**Details of the problem(s)**

16. Can you give me some details about your child’s behaviour?  
.....  
.....  
.....  
.....

17. When did this problem begin?  
.....

18. Have you any idea of what could have caused this problem?  
.....  
.....  
.....  
.....

19. Are there any times that you have noticed when the problem is better or worse?  
Better.....  
.....  
.....  
Worse.....  
.....  
.....

20. Where is this behaviour a problem?

At home

At School

Playing outside

At relative's house

During extra-curricular activities

Other (please explain).....

.....

.....

21. How well does your child interact with other children?

Very well

Average

Not very well

Not at all

22. How well does your child interact with other adults?

Very well

Average

Not very well

Not at all

23. Are there any other problems that may or may not be related to your child's behaviour?

None

Yes (please give details)

.....

.....

.....

.....

.....

24. Is there anything that I have not asked that you thought I might?

.....

.....

.....

.....

25. Do you have any questions?

**Thank you for meeting with me today and setting aside time to enable me to  
gain this important information.**

**Appendix 7b:** Family Background Questionnaire for parents with a  
learning disability



**POSITIVE PARENTING GROUP: FAMILY BACKGROUND  
QUESTIONNAIRE FOR PARENTS WITH A LEARNING DISABILITY**

Name\_\_\_\_\_Date of Birth\_\_\_\_\_Sex\_\_\_\_\_

Referred by\_\_\_\_\_GP\_\_\_\_\_

Address\_\_\_\_\_

POSTCODE\_\_\_\_\_Telephone Number\_\_\_\_\_

**Physical & Cognitive Status**

Any physical health problems e.g. epilepsy, asthma?\_\_\_\_\_

Can the person read?\_\_\_\_\_ write?\_\_\_\_\_

**Educational & Social History**

Schools attended\_\_\_\_\_

Qualifications received\_\_\_\_\_

Highest Level of education (please tick):

- Less than secondary school [ ]
- Secondary school [ ]
- Trade/apprenticeship [ ]
- Diploma/college qualification [ ]

History of care e.g. institutionalisation/brought up in family home \_\_\_\_\_

**Marital Status (tick)**

Single [ ]  
 Married [ ]  
 Co-habiting [ ]  
 Separated [ ]  
 Widowed [ ]  
 Divorced [ ]

Other Significant information? E.g. married for second time\_\_\_\_\_

<b>Living Arrangements (tick)</b>
-----------------------------------

Living alone with child	
Living with child and husband/partner	
Living with child and parents	
Does anyone else live with the client and their child? (e.g. family/friends) _____	

Does the client live with their child full or part-time? \_\_\_\_\_

If part-time, how often does their child stay with /visit them? \_\_\_\_\_

Type of accommodation (e.g. own house/council owned/supported accommodation etc) \_\_\_\_\_

<b>Details of employment/ activities</b>
--

Employment	Activities/Commitments/Involvement in the community e.g. clubs
Employment:	
paid/voluntary (please circle)	
Hours of work	

Times when can attend group \_\_\_\_\_

Details of partner's employment \_\_\_\_\_

Has the person previously been involved in a parenting training program? \_\_\_\_\_

<b>DETAILS ABOUT THE CLIENT'S CHILD(REN)</b>
--

Number of children\_\_\_ Date of Birth & sex of child(ren) \_\_\_\_\_

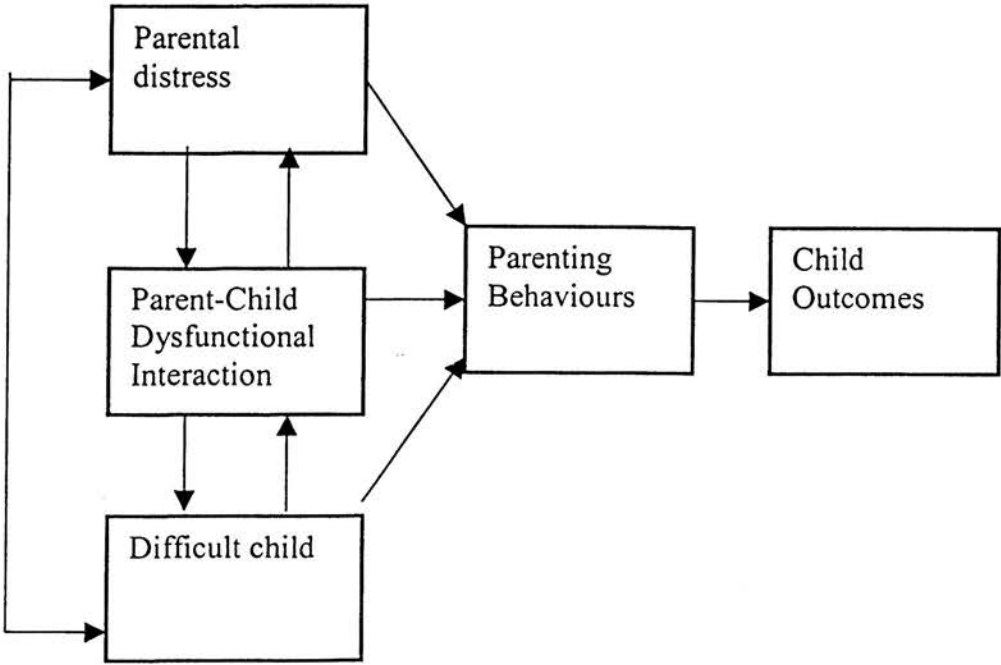
What is the client's relationship to the child? e.g. biological parent/foster/step \_\_\_\_\_

Has child ever been removed from their care? Yes No

Is their child on the child protection register? Yes No

**Appendix 8a:** Theoretical model for short-form Parental Stress Index

**Theoretical model for the PSI/SF.**



**Appendix 8b:**            Original Parental Stress Index

# PSI Short Form

## Instructions

This questionnaire contains 36 statements. Read each statement carefully. For each statement, please focus on the child you are most concerned about, and circle the response that best represents your opinion.

Circle the SA if you strongly agree with the statement.

Circle the A if you agree with the statement.

Circle the NS if you are not sure.

Circle the D if you disagree with the statement.

Circle the SD if you strongly disagree with the statement.

For example, if you sometimes enjoy going to the movies, you would circle A in response to the following statement:

I enjoy going to the movies.      SA   A   NS   D   SD

While you may not find a response that exactly states your feelings, please circle the response that comes closest to describing how you feel. YOUR FIRST REACTION TO EACH QUESTION SHOULD BE YOUR ANSWER.

Circle only one response for each statement, and respond to all statements. **DO NOT ERASE!** If you need to change an answer, make an "X" through the incorrect answer and circle the correct response. For example:

I enjoy going to the movies.      SA   A   NS   ~~A~~   SD

Before responding to the statements, write your name, gender, date of birth, ethnic group, marital status, child's name, child's gender, child's date of birth, and today's date in the spaces at the top of the questionnaire.

SA = Strongly Agree

A = Agree

NS = Not Sure

D = Disagree

SD = Strongly Disagree

1. I often have the feeling that I cannot handle things very well.	SA	A	NS	D	SD
2. I find myself giving up more of my life to meet my children's needs than I ever expected.	SA	A	NS	D	SD
3. I feel trapped by my responsibilities as a parent.	SA	A	NS	D	SD
4. Since having this child, I have been unable to do new and different things.	SA	A	NS	D	SD
5. Since having a child, I feel that I am almost never able to do things that I like to do.	SA	A	NS	D	SD
6. I am unhappy with the last purchase of clothing I made for myself.	SA	A	NS	D	SD
7. There are quite a few things that bother me about my life.	SA	A	NS	D	SD
8. Having a child has caused more problems than I expected in my relationship with my spouse (male/female friend).	SA	A	NS	D	SD
9. I feel alone and without friends.	SA	A	NS	D	SD
10. When I go to a party, I usually expect not to enjoy myself.	SA	A	NS	D	SD
11. I am not as interested in people as I used to be.	SA	A	NS	D	SD
12. I don't enjoy things as I used to.	SA	A	NS	D	SD
13. My child rarely does things for me that make me feel good.	SA	A	NS	D	SD
14. Most times I feel that my child does not like me and does not want to be close to me.	SA	A	NS	D	SD
15. My child smiles at me much less than I expected.	SA	A	NS	D	SD
16. When I do things for my child, I get the feeling that my efforts are not appreciated very much.	SA	A	NS	D	SD
17. When playing, my child doesn't often giggle or laugh.	SA	A	NS	D	SD
18. My child doesn't seem to learn as quickly as most children.	SA	A	NS	D	SD
19. My child doesn't seem to smile as much as most children.	SA	A	NS	D	SD
20. My child is not able to do as much as I expected.	SA	A	NS	D	SD
21. It takes a long time and it is very hard for my child to get used to new things.	SA	A	NS	D	SD
For the next statement, choose your response from the choices "1" to "5" below.					
22. I feel that I am:	1	2	3	4	5
1. not very good at being a parent					
2. a person who has some trouble being a parent					
3. an average parent					
4. a better than average parent					
5. a very good parent					
23. I expected to have closer and warmer feelings for my child than I do and this bothers me.	SA	A	NS	D	SD
24. Sometimes my child does things that bother me just to be mean.	SA	A	NS	D	SD
25. My child seems to cry or fuss more often than most children.	SA	A	NS	D	SD
26. My child generally wakes up in a bad mood.	SA	A	NS	D	SD
27. I feel that my child is very moody and easily upset.	SA	A	NS	D	SD
28. My child does a few things which bother me a great deal.	SA	A	NS	D	SD
29. My child reacts very strongly when something happens that my child doesn't like.	SA	A	NS	D	SD
30. My child gets upset easily over the smallest thing.	SA	A	NS	D	SD
31. My child's sleeping or eating schedule was much harder to establish than I expected.	SA	A	NS	D	SD
For the next statement, choose your response from the choices "1" to "5" below.					
32. I have found that getting my child to do something or stop doing something is:	1	2	3	4	5
1. much harder than I expected					
2. somewhat harder than I expected					
3. about as hard as I expected					
4. somewhat easier than I expected					
5. much easier than I expected					
For the next statement, choose your response from the choices "10+" to "1-3."					
33. Think carefully and count the number of things which your child does that bother you.	10+	8-9	6-7	4-5	1-3
For example: dawdles, refuses to listen, overactive, cries, interrupts, fights, whines, etc.					
34. There are some things my child does that really bother me a lot.	SA	A	NS	D	SD
35. My child turned out to be more of a problem than I had expected.	SA	A	NS	D	SD
36. My child makes more demands on me than most children.	SA	A	NS	D	SD

## **Appendix 8c:**

## **Adapted Parental Stress Index**



**Parental Stress Index– Adapted instructions & scoring for parents with learning disabilities**

I am going to read out some sentences to you about how you might feel about your child. For most of the questions, when I have finished I would like you to tell me (or point to using the laminated cards):

YES if this is true (point to tick),



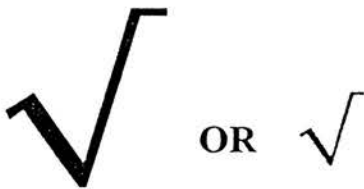
NO if this is not true (point to cross)



Or you can say you DON'T KNOW (point to question mark).



When you have chosen YES I will ask you to tell me if this is a very big yes, meaning that you strongly agree (point to big tick) or a little yes, meaning that you agree (point to small tick)



When you have chosen NO I will ask you to tell me if this is a very big no, meaning that you strongly disagree (point to big no) or a little no, meaning that you disagree (point to small no)



Lets practice. What would you say if I read out "I enjoy going shopping?"  
For questions 22, 32 and 33 there are some bar charts to help you decide your answer.

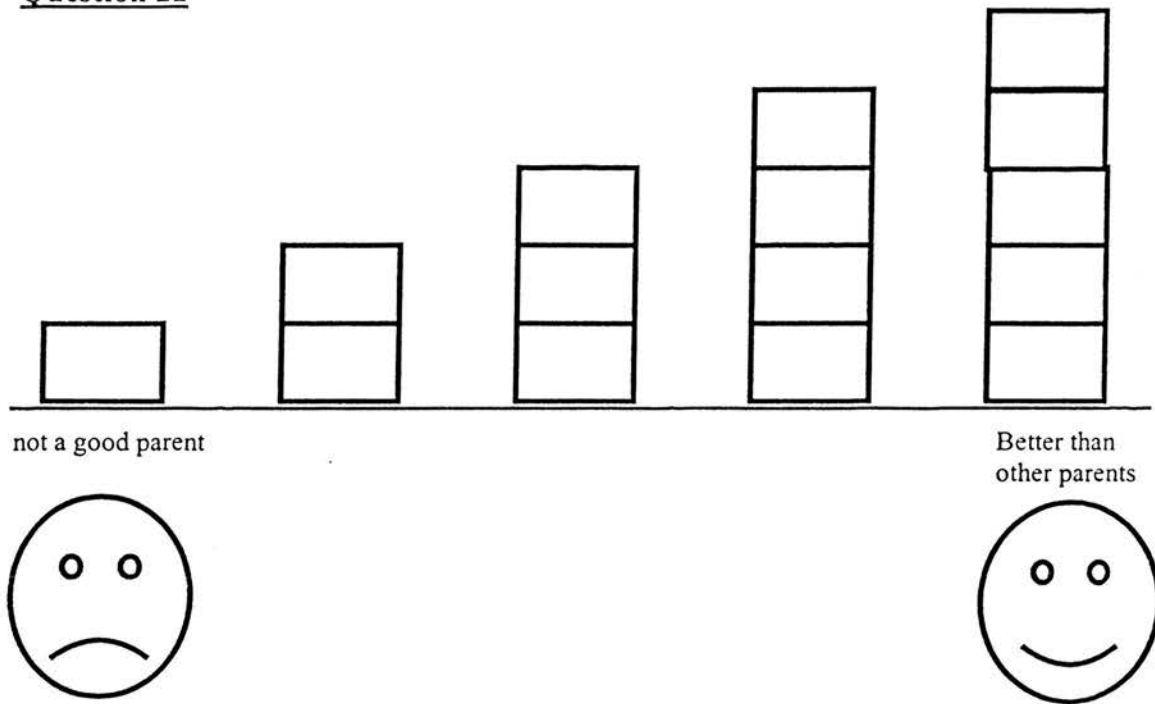
**Parental Stress Index – Adapted for parents with learning disabilities**

		5	4	3	2	1
1	I feel I do not handle things well	SA	A	NS	D	SD
2	I have had to give up more of my life to help my child than I thought	SA	A	NS	D	SD
3	I feel trapped by all the jobs as I have to do as a parent	SA	A	NS	D	SD
4	Since having this child, I have not been able to do new things	SA	A	NS	D	SD
5	Since having a child, I am not able to do the things I like	SA	A	NS	D	SD
6	I am not happy with the last clothes I bought	SA	A	NS	D	SD
7	There a few things that I do not like about my life	SA	A	NS	D	SD
8	Having a child has caused more problems than I thought with my boy/girl friend/husband/wife	SA	A	NS	D	SD
9	I feel lonely and that I have no friends	SA	A	NS	D	SD
10	When I go to a party I do not think that I will enjoy myself	SA	A	NS	D	SD
11	I am not as interested in people as I used to be	SA	A	NS	D	SD
12	I don't enjoy things I used to	SA	A	NS	D	SD
	<b>Parental Distress Score (PD)</b>					
	<b>Defensive Responding (DR)</b>					
13	My child hardly ever does things for me that make me feel good	SA	A	NS	D	SD
14	Most times I feel that my child does not like me or want to be close to me	SA	A	NS	D	SD
15	My child smiles at me much less than I thought	SA	A	NS	D	SD
16	When I do things for my child, I feel that he/she does not realise what I have done for them	SA	A	NS	D	SD
17	When my child plays he/she does not laugh much	SA	A	NS	D	SD
18	My child doesn't learn as quickly as most children	SA	A	NS	D	SD
19	My child doesn't smile as much as most children	SA	A	NS	D	SD
20	My child is not able to do as much as I thought	SA	A	NS	D	SD
21	My child finds it hard to get used to new things and sometimes takes a long time	SA	A	NS	D	SD
22	As a parent I feel that I am: <b>(using visual aid)</b> <ul style="list-style-type: none"> <li>• Not very good (5)</li> <li>• Quite good but with some difficulties (4)</li> <li>• As good as other parents (3)</li> <li>• Better than other parents (2)</li> <li>• Much better than other parents (1)</li> </ul>	5	4	3	2	1
23	I thought I would have nicer feelings for my child which upsets me	SA	A	NS	D	SD
24	Sometimes my child does things to upset me just to be mean	SA	A	NS	D	SD
	<b>Parent-Child Dysfunctional Interaction (P-CDI)</b>					
25	My child cries more than other children	SA	A	NS	D	SD
26	My child mostly wakes up in a bad mood	SA	A	NS	D	SD

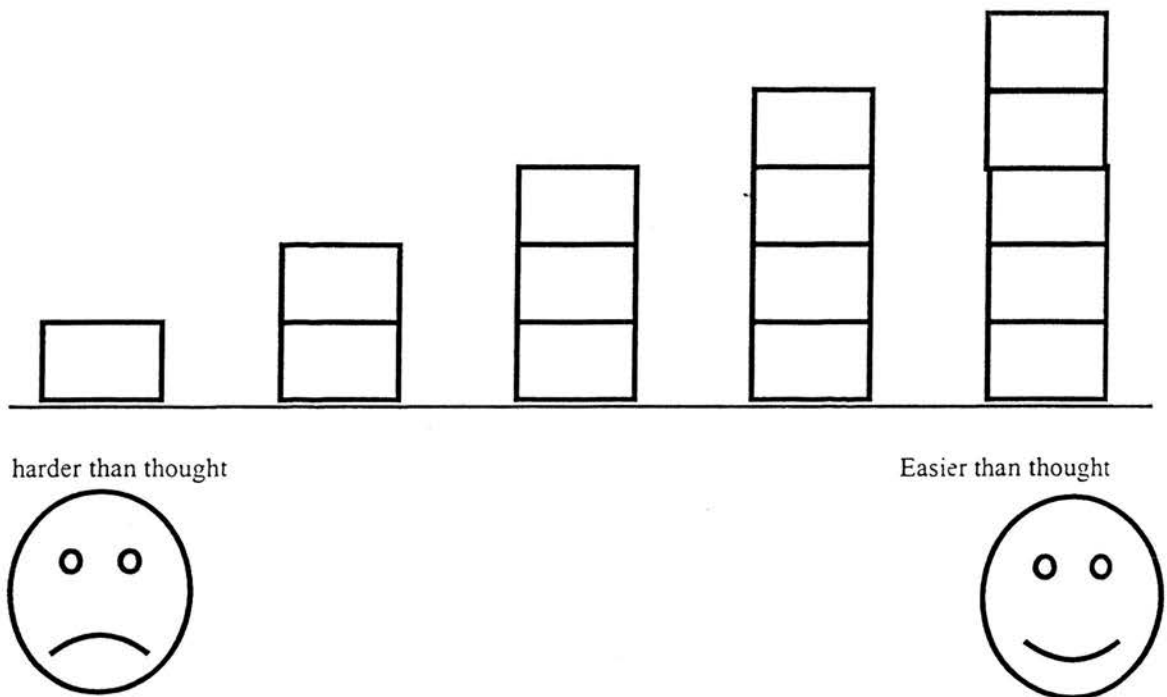
27	My child is very moody and upset easily	SA	A	NS	D	SD
28	My child does a few things which upset me a lot	SA	A	NS	D	SD
29	My child gets very upset when something happens that they do not like	SA	A	NS	D	SD
30	My child gets upset easily over small things	SA	A	NS	D	SD
31	My child's sleeping or eating routine was much harder to do than I thought	SA	A	NS	D	SD
32	I have found that getting my child to do something or stop doing something is <b>(use visual aid)</b> <ul style="list-style-type: none"> <li>• Much harder than I thought (5)</li> <li>• A little harder than I thought (4)</li> <li>• About as hard as I thought (3)</li> <li>• A little easier than I thought (2)</li> <li>• Much easier than I thought (1)</li> </ul>	5	4	3	2	1
33	Using the diagram, how many things from (0-10) does your child do that upsets you. For example, not listening, fighting, crying	SA	A	NS	D	SD
34	Some things my child does really upsets me a lot	SA	A	NS	D	SD
35	My child is more of a problem than I had thought	SA	A	NS	D	SD
36	My child asks me for more things than most children	SA	A	NS	D	SD
	<b>Difficult Child Score (DC)</b>					
	<b>Total Parental Stress Score</b>					

PSI- Question 22& 32– Visual aid for responding

Question 22

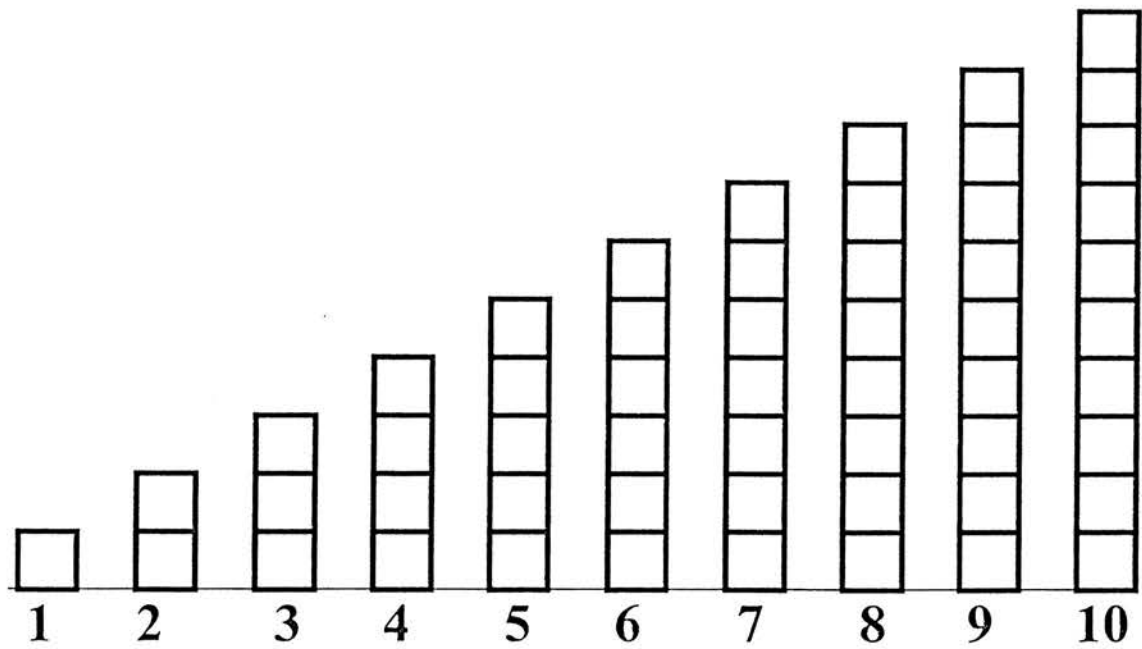


Question 32



**PSI- Question 33- Visual aid for responding**

The number of things my child does to annoy me:



## **Appendix 9a:** Original Hospital and Anxiety Depression Scale

# The Hospital Anxiety and Depression Scale

Name ..... Date .....

Clinicians are aware that emotions play an important part in most illnesses. If your clinician knows about these feelings she or he will be able to help you more.

This questionnaire is designed to help your clinician to know how you feel. Ignore the numbers printed on the left of the questionnaire. Read each item and underline the reply which comes closest to how you have been feeling in the past week.

Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought-out response.

A  
3  
2  
1  
0

**I feel tense or 'wound up':**

- Most of the time
- A lot of the time
- From time to time, occasionally
- Not at all

D  
0  
1  
2  
3

**I still enjoy the things I used to enjoy:**

- Definitely as much
- Not quite so much
- Only a little
- Hardly at all

A  
3  
2  
1  
0

**I get a sort of frightened feeling as if something awful is about to happen:**

- Very definitely and quite badly
- Yes, but not too badly
- A little, but it doesn't worry me
- Not at all

(continued overleaf)

# THE HOSPITAL ANXIETY AND DEPRESSION SCALE

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fold along dashed line

I can laugh and see the funny side of things:

- As much as I always could
- Not quite so much now
- Definitely not so much now
- Not at all

Worrying thoughts go through my mind:

- A great deal of the time
- A lot of the time
- From time to time but not too often
- Only occasionally

I feel cheerful:

- Not at all
- Not often
- Sometimes
- Most of the time

I can sit at ease and feel relaxed:

- Definitely
- Usually
- Not often
- Not at all

I feel as if I am slowed down:

- Nearly all the time
- Very often
- Sometimes
- Not at all

I get a sort of frightened feeling like 'butterflies' in the stomach:

- Not at all
- Occasionally
- Quite often
- Very often

(continued overleaf)

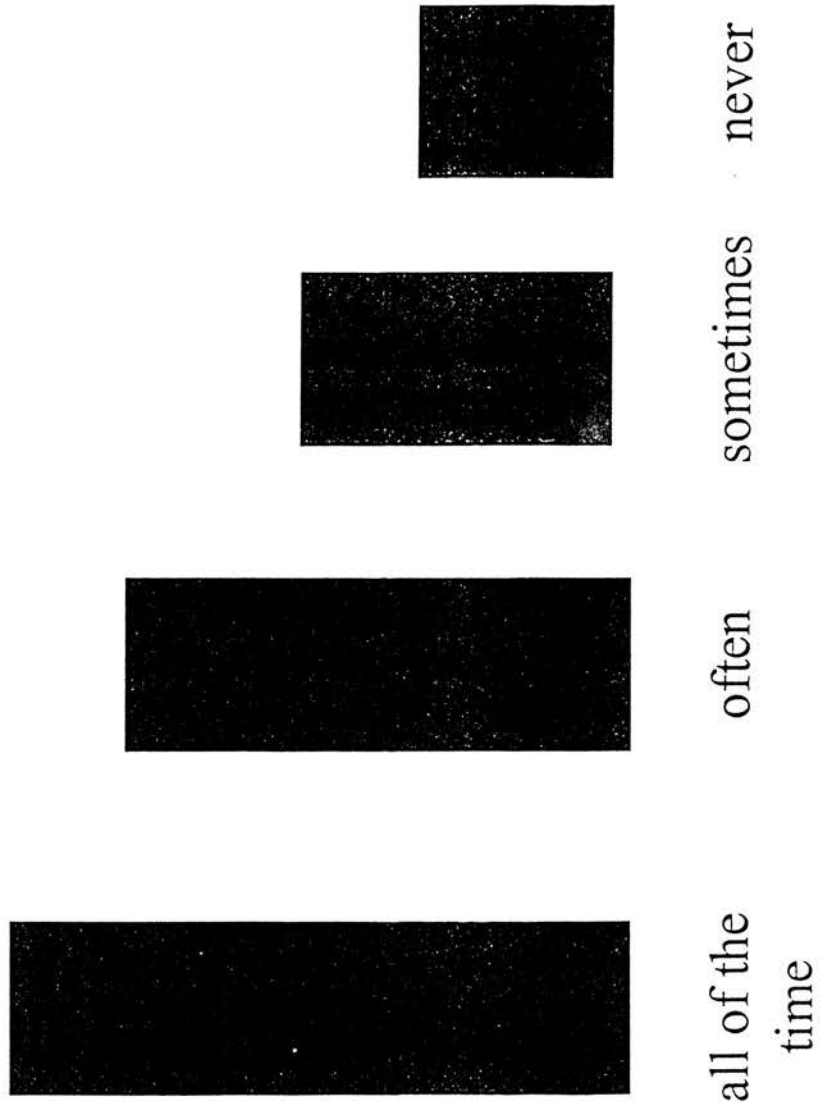


# THE HOSPITAL ANXIETY AND DEPRESSION SCALE

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## **Appendix 9b:** Adapted Hospital and Anxiety Depression Scale

1. I feel tense or ‘wound up’.  
(‘up tight’)



2. I still enjoy the things I used to enjoy.  
(have fun)



as much as  
before/usual



a little bit  
less than  
before/usual



less than  
before/usual



a lot less  
than  
before/usual

3. I feel sort of frightened as if something  
very bad is about to happen.



all of the  
time



often



sometimes



never

# 4. I like to laugh and fool about.



as much as  
before/usual



a little bit  
less than  
before/usual



less than  
before/usual



a lot less  
than  
before/usual

## 5. I have worrying thoughts.



all of the  
time



often



sometimes



never

6. I feel cheerful.  
(happy)



never



sometimes



often



all of the  
time



7. I can sit still and feel relaxed.  
(calm)



all of the  
time



often



sometimes



never

8. I feel as if I am slowed down.  
(no energy)



all of the  
time

often

sometimes

never

9. I get a sort of frightened feeling-  
like a funny feeling in the tummy.



all of the  
time



often



sometimes



never

# 10. I take care about how I look.



as much as  
before/usual



a little bit  
less than  
before/usual



less than  
before/usual



a lot less  
than  
before/usual

11. I feel restless and fidgety.



all of the  
time



often



sometimes



never

12. I get a nice feeling when I think about things I'm going to do.



as much as  
before/usual



a little bit  
less than  
before/usual



less than  
before/usual



a lot less  
than  
before/usual

13. I get sudden feelings of being  
really worried.



all of the  
time



often



sometimes



never

# 14. I like listening to music or watching television or videos.



as much as  
before/usual



a little bit  
less than  
before/usual



less than  
before/usual



a lot less  
than  
before/usual



Participant No.	
Administrator	
Date	/ /

## Adapted Hospital Anxiety & Depression Scale for Learning Disabilities – Score Sheet

1. I feel tense or 'wound up'. (‘up tight’)	All of the time 3	Often 2	Sometimes 1	Never 0
2. I still enjoy the things I used to enjoy. (have fun)	As much as before/usual 0	A little bit less than before/usual 1	Less than before/usual 2	A lot less than before/usual 3
3. I feel sort of frightened as if something very bad is about to happen.	All of the time 3	Often 2	Sometimes 1	Never 0
4. I like to laugh and fool about.	As much as before/usual 0	A little bit less than before/usual 1	Less than before/usual 2	A lot less than before/usual 3
5. I have worrying thoughts.	All of the time 3	Often 2	Sometimes 1	Never 0
6. I feel cheerful. (happy)	Never 3	Sometimes 2	Often 1	All of the time 0
7. I can sit still and feel relaxed. (calm)	All of the time 0	Often 1	Sometimes 2	Never 3
8. I feel as if I am slowed down. (no energy)	All of the time 3	Often 2	Sometimes 1	Never 0
9. I get a sort of frightened feeling – like a funny feeling in the tummy.	Never 0	Sometimes 1	Often 2	All of the time 3
10. I take care about how I look.	As much as before/usual 0	A little bit less than before/usual 1	Less than before/usual 2	A lot less than before/usual 3
11. I feel restless and fidgety.	All of the time 3	Often 2	Sometimes 1	Never 0
12. I get a nice feeling when I think about things I’m going to do.	As much as before/usual 0	A little bit less than before/usual 1	Less than before/usual 2	A lot less than before/usual 3
13. I get sudden feelings of being really worried.	All of the time 3	Often 2	Sometimes 1	Never 0
14. I like listening to music or watching television or videos.	As much as before/usual 0	A little bit less than before/usual 1	Less than before/usual 2	A lot less than before/usual 3

Depression Score:

Anxiety Score:

Total Score:

CATEGORY:

**Appendix 10a:**      Revised Rutter Child Behaviour Scales

# REVISED RUTTER PARENT SCALE FOR SCHOOL-AGE CHILDREN



Child's name: \_\_\_\_\_ Age: \_\_\_\_\_

Below are a series of descriptions of behaviour often shown by children. After each statement are three columns: *Does not apply*, *Applies somewhat* and *Certainly applies*. If your child definitely shows the behaviour described by the statement, place a cross in the box under column 3 *Certainly applies*. If your child shows the behaviour described by the statement but to a lesser degree or less often, place a cross in the box under column 2 *Applies somewhat*. If, as far as you are aware, your child does not show the behaviour, place a cross in the box under column 1 *Does not apply*.

Please complete on the basis of your child's behaviour *during the past three months*.

Put *one* cross against *each* statement. Thank you.

This statement ...

- 1. Tries to be fair in games
- 2. Very restless, has difficulty staying seated for long
- 3. Considerate of other people's feelings
- 4. Squirmy, fidgety child
- 5. Often destroys or damages own or others' property
- 6. Has had tears on arrival at school or has refused to go into the building in the past 12 months
- 7. Will try to help someone who has been hurt
- 8. Frequently fights or is extremely quarrelsome with other children
- 9. Gives up easily
- 10. Not much liked by other children
- 11. Volunteers to help around the house or garden
- 12. Often worried, worries about many things
- 13. Tends not to finish things started, short attention span
- 14. Spontaneously affectionate to family members
- 15. Tends to be on own, rather solitary

Does not apply	Applies somewhat	Certainly applies
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



his statement ...

Irritable, touchy, is quick to 'fly off the handle'

Kind to younger children

Often appears miserable, unhappy, tearful or distressed

Resentful or aggressive when corrected

Blames others for things

Comforts a child who is crying or upset

Has a stutter or stammer

Has other speech difficulty

Truants from school

Has twitches, mannerisms, or tics of the face and body

Frequently sucks thumb or finger

Gets on well with other children

Has stolen things on more than one occasion in the past 12 months

Cries easily

Frequently bites nails or fingers

Often disobedient

Attempts to stop quarrels or fights

Wet or soiled self this year

Cannot settle to anything for more than a few moments

Peaceful, determined child

Does not apply

Applies somewhat

Certainly applies

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This statement ...

**Does not apply**  
**Applies somewhat**  
**Certainly applies**

36. Shares out treats with friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37. Tends to be fearful or afraid of new things or new situations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38. Kicks or bites other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39. Stares into space, stares blankly	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40. Plays imaginatively, enjoys 'pretend' games	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
41. Fussy, or over-particular child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
42. Inattentive, easily distracted	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
43. Independent, confident child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
44. Doesn't share toys	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
45. Helps other children who are feeling ill	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
46. Often tells lies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
47. Bullies other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
48. Kind to animals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
49. Often complains of aches or pains	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
50. Inconsiderate of others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Completed by: \_\_\_\_\_

Date of completion: \_\_\_\_\_

Signed: \_\_\_\_\_

Thank you for your help in this study.

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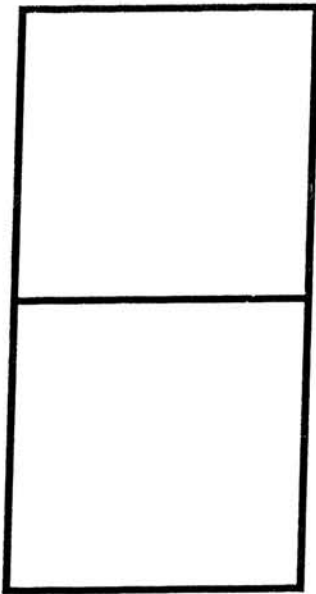
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**Appendix 10b:**      Adapted Rutter Child Behaviour Scales

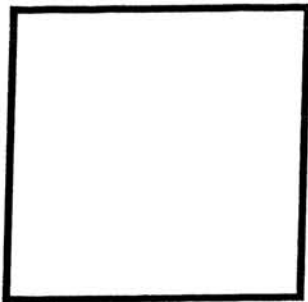
**Revised Rutter Child Behaviour Scales - Adapted instructions and scoring for parents with learning disabilities**

I am going to read out some sentences about children. After I have read the sentence, using the diagram below, please tell me if you think this is **ALWAYS** like your child, **SOMETIMES** like your child or **NEVER** like your child:



2

**ALWAYS**



1

**SOMETIMES**



0

**NEVER**

		Never	Sometimes	Always
1	Tries to be fair in games	0	1	2
2	Finds it hard to stay in seat	0	1	2
3	Thinks about other people's feelings	0	1	2
4	Fidgety (e.g. moves fingers a lot, fiddles with hair)	0	1	2
5	Destroys things that belong to other people	0	1	2
6	Has had tears when taken to school or has not wanted to go into school for the past year	0	1	2
7	Will try to help someone who has been hurt	0	1	2
8	Fights or has arguments with other children	0	1	2
9	Gives up easily	0	1	2
10	Other children don't seem to like my child	0	1	2
11	Asks to help around the house or garden	0	1	2
12	Worries about many things a lot	0	1	2
13	Does not pay attention and does not finish tasks	0	1	2
14	Is loving and caring towards people in the family without asking them to be	0	1	2
15	Prefers to do things on own	0	1	2
16	Has a bad temper and gets angry easily	0	1	2
17	Kind to younger children	0	1	2
18	Looks sad and unhappy	0	1	2
19	Gets bad tempered and moody when told not to do something	0	1	2
20	Blames other people for things	0	1	2
21	Helps/cares for a child who is upset	0	1	2
22	Stammers with some words (e.g. when trying to say mum will say m m m mum)	0	1	2
23	Finds other things about talking difficult	0	1	2
24	Often does not go to school	0	1	2
25	Face and body can twitch sometimes (i.e. make a small sudden movement)	0	1	2
26	Suck thumb or finger	0	1	2
27	Gets on well with other children	0	1	2
28	Has stolen something one time or more over the last year	0	1	2
29	Cries easily	0	1	2
30	Bites nails or fingers a lot	0	1	2
31	Does not do what I ask him	0	1	2
32	Tries to stop arguments or fights	0	1	2



33	Has had accidents with wetting and pooing this year	0	1	2
34	Tries hard to get own way	0	1	2
35	Blames others for things	0	1	2
36	Shares sweets with friends	0	1	2
37	Tends to be afraid of new things, places or people	0	1	2
38	Kicks or bites other children	0	1	2
39	Stares as if looking at nothing	0	1	2
40	Likes to play pretend or make-believe games	0	1	2
41	Is a fussy child	0	1	2
42	Does not pay attention and looks at other things	0	1	2
43	Can manage a lot of things on their own and doesn't need lot of help	0	1	2
44	Doesn't let other children play with their toys	0	1	2
45	Helps other children who are feeling ill	0	1	2
46	Tells lies a lot	0	1	2
47	Picks on and is nasty to other children	0	1	2
48	Kind to animals	0	1	2
49	Often speaks about things being sore	0	1	2
50	Does not think about other people	0	1	2

**Appendix 11a:** Supports included in Family Support Scale

**Categories and sub-categories of the Family Support Scale.**

Category	Items included
Partner/spouse support	<ul style="list-style-type: none"><li>• Partner's parents</li><li>• Partner's relatives</li><li>• Partner</li></ul>
Friendship	<ul style="list-style-type: none"><li>• Friends</li><li>• Partner's friends</li><li>• Own children</li><li>• Other parents</li><li>• Place of worship</li></ul>
Family	<ul style="list-style-type: none"><li>• Parents</li><li>• Relatives</li></ul>
Social organisations	<ul style="list-style-type: none"><li>• Co-workers</li><li>• Parent groups</li><li>• Social groups/clubs</li><li>• School/day-care centre</li></ul>
Professional services	<ul style="list-style-type: none"><li>• Doctor</li><li>• Professional helpers (e.g. social workers)</li><li>• Professional agencies (e.g. mental health)</li><li>• Early intervention programme</li></ul>

**Appendix 11b:**      Family Support Scale

# FAMILY SUPPORT SCALE (FSS)

## (ADAPTED FROM DUNST, JENKINS AND TRIVETTE)

Listed below are sources of support that are often helpful to members of families raising a young child. This questionnaire asks you to indicate how helpful each source is to *your family*.

Please *circle* the response that best describes how helpful the sources have been to your family during the past 3 to 6 months. If a source of help has not been available to your family during this period of time, circle the NA (not available) response.

**Not available**   **Not helpful at all**   **Sometimes helpful**   **Generally helpful**   **Very helpful**   **Extremely helpful**

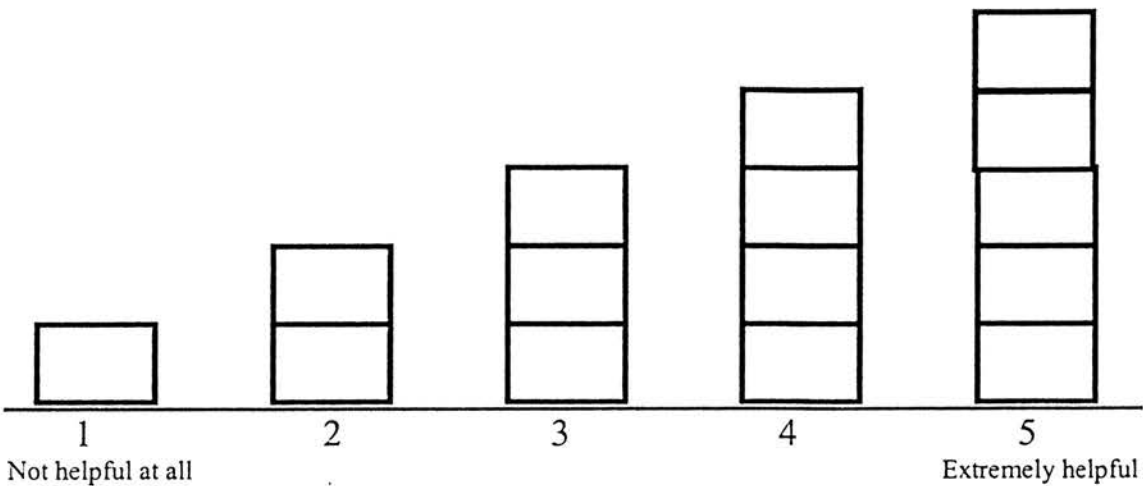
1. My parents	NA	1	2	3	4	5
2. My partner/spouse's parents	NA	1	2	3	4	5
3. My relatives/kin	NA	1	2	3	4	5
4. My partner/spouse's relatives/kin	NA	1	2	3	4	5
5. Partner/spouse	NA	1	2	3	4	5
6. My friends	NA	1	2	3	4	5
7. My partner/spouse's friends	NA	1	2	3	4	5
8. My own children	NA	1	2	3	4	5
9. Other parents	NA	1	2	3	4	5
10. Co-workers	NA	1	2	3	4	5
11. Parent groups	NA	1	2	3	4	5
12. Social groups/clubs	NA	1	2	3	4	5
13. Place of worship/religious organization	NA	1	2	3	4	5
14. My family or child's doctor	NA	1	2	3	4	5
15. Professional helpers (social workers, therapists, teachers, etc.)	NA	1	2	3	4	5
16. Professional agencies (public health, social services, mental health, etc)	NA	1	2	3	4	5
17. School/day-care centre	NA	1	2	3	4	5
18. Early intervention programme	NA	1	2	3	4	5
19. _____	NA	1	2	3	4	5
20. _____	NA	1	2	3	4	5



© 1993, Dunst, Trivette and Hamby. *Family Support Scale* by Carl J. Dunst, Carol M. Trivette and Debora Hamby from Dunst, C. J., Trivette, C. M. and Deal, A. G. (Eds) (1994). *Supporting and Strengthening Families: Volume 1: Methods, Strategies and Practices*. Reproduced by kind permission of the authors and published by Brookline Books, Cambridge, MA.

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Visual Aid for Family Support Scale



## **Appendix 12:** Parenting Skills Assessment

## **Parenting Skills Assessment for parents with learning disabilities**

At one time or another all children can behave badly or do things that parents don't like. For example children may hit someone, throw food or not pick up their toys.

Parents have lots of different ways of dealing with these problems. This survey is to find out how you deal with difficult situations. Remember that we can all find children very hard work and there is no "wrong" answer. The survey is to find out what you might like help with as a parent.

---

**(1) When my child has done something good I say "well done"**

Always

Sometimes

Never

**(2) I reward (give my child something) for good behaviour**

Always

Sometimes

Never

**(3) I can think of different rewards to give my child**

Always

Sometimes

Never

Example \_\_\_\_\_  
\_\_\_\_\_

**(4) When I spend time with my child I can think nice things to do or talk about with them**

Always

Sometimes

Never

Example(s) \_\_\_\_\_  
\_\_\_\_\_

**(5) If saying "no" doesn't work with my child I try other kinds of things**

Always

Sometimes

Never

Example(s) \_\_\_\_\_  
\_\_\_\_\_

**(6) I find I can show my child affection (e.g. kiss and cuddle, say nice things)**

Always

Sometimes

Never



**(7) When my child has done something wrong I**

**a) Use time-out (e.g. put them in an another room to calm down)**

Always                      Sometimes                      Never

**b) Smack them**

Always                      Sometimes                      Never

**c) Shout/lose my temper and get into a long argument**

Always                      Sometimes                      Never

**d) Ignore them or walk away**

Always                      Sometimes                      Never

**e) Take away something they don't like/stop them from doing something**

Always                      Sometimes                      Never

**f) Swear or call my child names**

Always                      Sometimes                      Never

Other \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**(8) When my child does something I don't like I do something about it**

**(a) Right away**

Always                      Sometimes                      Never

**(b) Every time it happens**

Always                      Sometimes                      Never

**(9) I set limits/have rules on what my child is allowed to do**

Always                      Sometimes                      Never

Example(s) \_\_\_\_\_  
\_\_\_\_\_

**(10) When I say “no” to my child I let them do it anyway**

Always

Sometimes

Never

Example(s) \_\_\_\_\_  
\_\_\_\_\_

**(11) I say I will punish my child and then not do it**

Always

Sometimes

Never

Example(s) \_\_\_\_\_  
\_\_\_\_\_

**(12) When my child is out of my sight (e.g. out playing) I know what they are doing**

Always

Sometimes

Never

**Appendix 13a:** Satisfaction questionnaire for parents without a learning disability

# Evaluation of Course

This is just a short form that will help us to get an idea of how useful this course has been.

Please circle one of the numbers next to each statement to let us know how much you agree with the 5 statements below.

- 1=Strongly agree
- 2=Agree
- 3=Unsure
- 4=Disagree
- 5=Strongly disagree

The information was understandable	1	2	3	4	5
The topics were relevant	1	2	3	4	5
Group participation was easy	1	2	3	4	5
I found the course useful	1	2	3	4	5
The way in which information was presented was good	1	2	3	4	5
I feel better equipped to deal with my child's behaviour	1	2	3	4	5

What aspect of the course did you find *most* useful?.....  
.....  
.....

What aspect of the course did you find *least* useful?.....  
.....  
.....

Are there any comments that you wish to make about anything related to the groups?  
.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....

Thank You

**Appendix 13b:** Satisfaction questionnaire for parents with a learning disability

### Satisfaction Questionnaire for parents with learning disabilities

This is just a short form that will help us to get an idea of how useful the parenting group has been. I will read you some statements. When I have finished I would like you to tell me (or point to):

YES if this is true (point to tick),



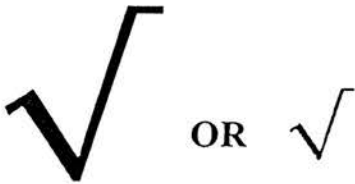
NO if this is not true (point to cross)



Or you can say you DON'T KNOW (point to question mark).



When you have chosen YES I will ask you to tell me if this is a very big yes, meaning that you **strongly agree** (point to big tick) or a little yes, meaning that you **agree** (point to small tick)



When you have chosen NO I will ask you to tell me if this is a very big no, meaning that you **strongly disagree** (point to big no) or a little no, meaning that you **disagree** (point to small no)



**Evaluation Form**

Scoring Key for interviewer – Strongly Agree (SA), Agree (A), Don't Know (DK), Disagree (D), Strongly Disagree(SD)

- |   |              |
|---|--------------|
| • I could understand the information                | SA A DK D SD |
| • The topics were important                         | SA A DK D SD |
| • I found it easy to join in the group              | SA A DK D SD |
| • I found the group useful                          | SA A DK D SD |
| • I liked the way the information was given         | SA A DK D SD |
| • I feel better able to manage my child's behaviour | SA A DK D SD |



The best thing about the group was...



The worst thing about the group was...

Is there anything else you would like to tell us about how you felt about the group?

**Appendix 14:**            Outline of Triple P programme



## Overview of Group Triple P Programme

<b><u>Session 1</u></b>  Positive Parenting	<ul style="list-style-type: none"><li>• Working as a group</li><li>• What is positive parenting?</li><li>• Causes of child behaviour problems</li><li>• Goals for change</li><li>• Keeping track of children's behaviour</li></ul>
<b><u>Session 2</u></b>  Promoting Children's Development	<ul style="list-style-type: none"><li>• Developing positive relationships with children</li><li>• Encouraging desirable behaviour</li><li>• Teaching new skills and behaviours</li></ul>
<b><u>Session 3</u></b>  Managing Misbehaviour	<ul style="list-style-type: none"><li>• Managing misbehaviour</li><li>• Developing parenting routines</li><li>• Behaviour charts</li></ul>
<b><u>Session 4</u></b>  Planning ahead	<ul style="list-style-type: none"><li>• Family survival tips</li><li>• High risk situations</li><li>• Planned activities routine</li></ul>
<b><u>Session 5</u></b>  Re-cap of course	<ul style="list-style-type: none"><li>• Maintenance of change</li><li>• Re-cap of course</li><li>• Success in implementing strategies at home</li></ul>

**Appendix 15 a:**      Original Triple P overhead

# Planned Activities Routines

(Set up a practice session)

- Prepare in advance
- Talk about rules
- Select engaging activities
- Use rewards for appropriate behaviour
- Use consequences for misbehaviour
- Hold a follow-up discussion

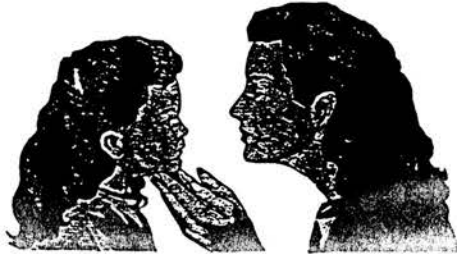
4.4  
Overhead



Appendix 15b:           Adapted Triple P overhead

## Going to the supermarket

1. Talk about the rules before you go



2. Keep them busy!

e.g. Please go and get me the carrots



Can you see the peas  
anywhere?



Praise when do these things!



3. Reward at end of the trip if been good –

4. If not gone well, talk about the rules & rewards for next time

